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ABSTRACT

This report provides lawyers and service providers with legal information and analysis about issues affecting persons with developmental disabilities and Acquired Immune Deficiency Syndrome (AIDS). The report reviews relevant medical facts, discusses federal and state laws which define the rights and responsibilities of disabled individuals and service providers, explains how these laws apply to persons with Human Immunodeficiency Virus (HIV) infection, and provides information for rational policymaking. The report offers a detailed review of five major areas of the law: antidiscrimination, HIV testing and medical treatment, confidentiality and provider liability, isolation and involuntary civil commitment, and federal benefit and entitlement programs. These areas are discussed in relation to topics such as housing and residential facilities, health care, child welfare services, day care and education, vocational training, and employment. Within the chapters, sections summarize the legal rules or principles, analyze major statutes and legal principles, and pose a series of questions and provide answers applying the laws to practical situations. A glossary and approximately 250 references are included. (JDD)

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AIDS and Persons with Developmental Disabilities: The Legal Perspective

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AIDS AND PERSONS WITH DEVELOPMENTAL DISABILITIES: THE LEGAL PERSPECTIVE

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Commission on the Mentally Disabled
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Commission on the Mentally Disabled

The ABA established the Commission on the Mentally Disabled in 1973 to help individuals with mental disabilities obtain adequate treatment in humane environments and to safeguard their basic rights. Since then, the Commission has served actively to integrate the disciplines of law and mental health to promote the rights of persons with mental and physical disabilities. Commission members have included lawyers, psychiatrists, psychologists, judges, consumer representatives and mental health administrators.

The Commission's primary, and longest-running project — *The Mental and Physical Disability Law Reporter* — is a bimonthly publication that is the only comprehensive source of information on legal, legislative and administrative developments in the rapidly expanding area of mental and physical disability law. The Commission also offers an on-line research data base which currently has all the case summaries from the *Reporter* for the last six years indexed by subject matter, as well as nearly 9,000 case citations going back to 1976. In guardianship, the Commission is developing best practices for monitoring and enforcing court orders; convening a national conference on court-related needs of elderly and disabled persons; developing a training module and conducting training on alternatives to guardianship. The Commission has developed a manual and VHS video training package on representing persons with mental illness in involuntary civil commitment hearings and will conduct training for using these materials. Finally, the Commission is examining outpatient civil commitment initiatives nationwide.

For more information on the Commission, please contact John Parry, Director, ABA Commission on the Mentally Disabled, 1800 M Street, N.W., Washington, D.C. 20036; 202/331-2240.

Center on Children and the Law

The mission of the ABA Center on Children and the Law is to improve the quality of life for children through advancements in law, justice and public policy.

The ABA Center on Children and the Law, a program of the ABA Young Lawyers Division, was established over 10 years ago to protect and promote children's interests under the law. Although the issues associated with this goal have been rapidly multiplying throughout the decade, the Center remains committed to this original mandate. Today, over 17 professional and support staff work on a range of issues, including: the prevention of child placements due to family homelessness; pediatric AIDS; parental drug abuse; child maltreatment; foster care and permanency planning; child welfare liability; drug-exposed infants; and child support enforcement.

The Center publishes the *ABA Juvenile and Child Welfare Law Reporter*, prepares the *Children's Legal Rights Journal*, and has produced over 60 curricula, monographs, reference manuals and reports.

The Center recently added a research component, a capacity to do first-rate social science research on issues affecting children who may be caught in the legal and judicial process. Center research has involved both elaborate social science studies on law-related subjects and pure legal research.

For more information on the Center, please contact Howard Davidson, Director, ABA Center on Children and the Law, 1800 M Street, N.W., Washington, D.C. 20036; 202/331-2250.

PREFACE AND ACKNOWLEDGEMENTS

In 1988, the American Bar Association's Commission on the Mentally Disabled and the Center on Children and the Law were awarded a grant by the United States Department of Health and Human Services, Administration on Developmental Disabilities, to provide lawyers and service providers with legal information and analysis about issues affecting persons with developmental disabilities and AIDS. Under the grant, the project will produce three products. The first is this report. The second product will be guidelines and model procedures for service providers addressing confidentiality issues. Third, the project created a developmental disabilities/AIDS legal research database as part of the ABA's Disability Law Network. The database contains a summary of federal and state AIDS-related court decisions and legislation, as well as abstracts of legal articles concerning AIDS-related issues.

Assisting the American Bar Association staff in its work is an advisory board comprised of distinguished experts from across the country. The board members met twice to identify the major issues to be addressed in the present report, and to review a draft. The board members are: The Hon. Richard T. Andrias, Justice of the New York State Supreme Court, New York, NY; Daniel R. Anderson, Assistant Attorney General, Baltimore, MD; Allen C. Crocker, M.D., Director, Developmental Evaluation Clinic, Children's Hospital Medical Center, Boston, MA; Curtis L. Decker, J.D., Executive Director, National Association of Protection and Advocacy Systems, Washington, D.C.; Chai Feldblum, Legislative Counsel, American Civil Liberties Union, Washington, D.C.; Wylda Hammond, M.D., Director, University Affiliated Training Program, Children's Hospital, Los Angeles, CA; Ruth Luckasson, Associate Professor, University of New Mexico, Albuquerque, NM; Arlene Mayerson, Directing Attorney, Disability Rights Education and Defense Fund, Berkeley, CA; Jean McGuire, Executive Director, AIDS Action Council, Washington, D.C.; Sheila Scriggins, M.S.W., A.C.S.W., Program Director, Black Church Foster Care Unit, Washington, D.C.; and Dr. Reed Tuckson, Commissioner of Public Health, Washington, D.C. The diverse backgrounds and expertise of the board members provided the staff with critical information and understanding in preparing this report. The project staff especially notes the assistance of Dr. Allen Crocker in developing the Medical Overview.

Susan Sherman, law clerk, provided invaluable assistance in researching cases, statutes, and articles, drafting the isolation and involuntary commitment chapter, checking all footnotes, and proofreading the report.

The project staff also expresses its deep appreciation to Bonnie Milstein, Senior Staff Attorney, Mental Health Law Project, for her contribution to the section on the Fair Housing Amendments Act. We express thanks to our project officer, Kay Smith, of the Administration on Developmental Disabilities, for her advice and guidance throughout this project. The project staff also wishes to thank Patricia Davidson and Mark Hardin for their review and commentary of the draft report. Finally, we thank Patricia McCormick and Sally Inada for their assistance on editing and production.

Sharon Rennert
December 1989

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I. INTRODUCTION

The Nature of the Problem

Since it first was identified in the United States ten years ago, Acquired Immune Deficiency Syndrome — AIDS* — has affected every segment of society and its institutions. Increasingly, the developmental disability (DD) community has been affected by this disease. Most infants born with HIV have developmental impairments, which can include mental retardation, cerebral palsy, and motor abnormalities. In addition, persons with developmental impairments also contract HIV. Although the number of persons with developmental disabilities and HIV infection currently is relatively small, HIV can be transmitted to children, adolescents, and adults with developmental disabilities.

In addressing the needs of persons with developmental impairments and HIV infection, programs are grappling with a variety of legal issues. Some are familiar questions with a new twist, such as determining competency to consent to testing and experimental treatments. Other questions, such as a residential facility's legal responsibility concerning the sexual activities of its residents, take on added urgency because of the risk of HIV infection. Another set of issues involve potential conflicts between competing interests; for example, preserving an HIV-positive client's confidentiality while ensuring that the medical condition is disclosed to the individuals who need this information in order to provide appropriate services.

Discrimination, which always has been a problem for persons with developmental disabilities, is made worse and more complicated with the addition of HIV infection. Often, HIV discrimination is hidden under irrational concerns about preventing transmission of the virus. Thus, the potential for discrimination against persons with developmental impairments and HIV infection is two-fold. The legal challenge for the DD community is to provide needed treatment and services to all persons with developmental disabilities who have HIV infection, or are at risk of contracting the virus; and to do so in least restrictive environments that will enable individuals to achieve their developmental potential and to preserve their rights.

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* At the outset, it is important to distinguish between AIDS and the Human Immunodeficiency Virus (HIV) which causes AIDS. AIDS cannot be spread from one person to another, but HIV can be passed to other people through specific body fluids. A person with HIV infection can have no outward symptoms of illness. HIV infection refers to all people with the virus, while AIDS refers only to those in the final stage of HIV infection who have specific illnesses and conditions. In recognition of changing medical terminology, newly-enacted statutes generally refer to HIV infection rather than AIDS. Following this trend, this report primarily uses the term HIV infection, referring to AIDS only when the latter is legally relevant.

Our Response to the Problem

This report provides agencies and professionals that serve persons with developmental disabilities with the information and analysis to assist them in meeting this legal challenge. The report discusses federal and state laws which define the rights and responsibilities of disabled individuals and service providers, explains how these laws apply to persons with HIV infection, and provides policymakers with information for rational policymaking.

The report is not intended as a comprehensive survey of the legal implications of HIV infection. The legal discussion focuses on a specific population: persons with developmental disabilities and HIV infection. As defined by the federal Developmental Disabilities Assistance and Bill of Rights Act, a developmental disability is a severe, chronic disability which:

a. is attributable to a mental or physical impairment or combination of mental and physical impairments;
b. is manifested before age 22;
c. is likely to continue indefinitely;
d. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated; and
e. results in substantial functional limitations in three or more of the following major life activities:

1. self-care
2. receptive and expressive language
3. learning
4. mobility
5. self-direction
6. capacity for independent living
7. economic self-sufficiency.[1]

This definition may cover a wide range of impairments, including mental retardation, cerebral palsy, Down's syndrome, autism, epilepsy, spina bifida -- and now, HIV infection. Some individuals have multiple developmental impairments. The degree of impairment of any disability can range from mild to profound and may involve mental or physical impairments.

This report offers a detailed review of five major areas of the law, and how they apply to persons with developmental disabilities and HIV infection: antidiscrimination, HIV testing and medical treatment, confidentiality and provider liability, isolation and involuntary civil commitment, and federal benefit and entitlement programs. These substantive areas are discussed in relation to important topics such as housing and residential facilities, health care, child welfare services, day care and education, vocational training, and employment. Since much of the case law concerning HIV infection is based on medical facts, the report begins with an overview of current medical knowledge.

With the exceptions of the medical overview and federal benefit chapters, the other chapters are divided into three sections. The first section summarizes the legal rules or principles in a

specific area of law. The second section provides an analysis of the major statutes and legal principles relevant to addressing questions concerning HIV infection and developmental disabilities. The third section poses a series of questions and provides answers, designed to apply the laws to practical situations confronting service providers and lawyers. Since relatively little case law exists which define the rights and responsibilities that pertain to persons with developmental disabilities and HIV infection, this report develops legal arguments and suggests possible answers that will be useful in resolving legal questions presented by HIV infection.

General Principles Used in the Report

In discussing specific legal questions, it is sometimes easy to lose sight of the forest for the trees. In reading the chapters that follow, and in developing and implementing policies that satisfy legal requirements, there are several broad principles that frequently recur.

1. HIV infection does not negate the legal rights and program entitlements of persons with developmental disabilities.

The fact that a person with a developmental disability also has HIV infection does not alter the basic legal rules. As with all HIV-positive individuals, those with developmental disabilities must give informed consent to HIV testing, are protected against discrimination and arbitrary isolation, and have a right to confidentiality of their HIV status. Yet while the basic rules remain the same, their application may differ as a result of the person's developmental impairment. For example, an adult with mental retardation may have a guardian with the power to make all medical decisions on behalf of the ward. This does not negate the informed consent requirement; it merely transfers consent authority to the guardian. The practical application of certain laws in a particular situation may appear cumbersome, but these requirements preserve vital interests of individual autonomy. Where legal rules may have unintended consequences that can hurt the interests of a person with a developmental disability, program providers and lawyers should work together to achieve appropriate modifications.

2. Generally, the law has applied existing rules and principles to resolve HIV-related questions.

"HIV law" is a misnomer. The law develops by analogy, taking new developments and placing them in existing legal constructs. Questions involving HIV infection are being answered with reference to existing statutes, regulations, and common law and constitutional principles applicable in similar situations. For example, state courts and administrative agencies have determined that HIV infection is a disability protected by existing antidiscrimination statutes; HIV-specific legislation is not necessary. Where new HIV-specific statutes have been enacted, their provisions parallel general disability antidiscrimination statutes.

In certain areas, particularly confidentiality, states have adopted HIV-specific laws that do not always have counterparts in existing statutes. The principles embodied in these statutes, however, are similar to long-standing legal and ethical obligations to maintain confidentiality of other types of sensitive information. In most instances, questions involving HIV infection can

best be answered by employing the decisionmaking process used for similar diseases or situations.

3. Policies and procedures for handling issues involving hepatitis B should be adapted to cover HIV infection and other similar infectious diseases. Programs lacking any such policies should develop and implement them as soon as possible.

HIV, like hepatitis B, can be transmitted through sexual contact or exposure to infected blood. Therefore, most considerations involving HIV transmission should be the same as considerations involving hepatitis B. There is no need to establish a separate set of rules for HIV.

If a program does not have any established policies it would be well advised to develop and implement such plans. Discussing many of the questions addressed in this report, before a client is diagnosed with HIV infection, can avoid much of the panic and confusion that faced many unprepared programs. Education programs, aimed at clients, their families and guardians, and staff members, can help alleviate fears and increase understanding. Policies and educational efforts should include mention of the legal rights and responsibilities of various parties, placed in the context of medical knowledge and program objectives. Adopting a policy that addresses all infectious diseases places HIV in a larger context and can emphasize the need for precautions to prevent a variety of consequences. Similarly, training on safer sexual practices can help individuals prevent all sexually transmitted diseases.

4. Decisions must be made on an individualized basis using the specific facts of each case.

One of the basic tenets of disability law is the need for individualized determinations. The effect of a disability on any given person can vary enormously, making generalizations an extremely unreliable foundation for decisionmaking. This truism holds for HIV infection. First, the disease does not necessarily run a stable course; there can be periods of extreme illness followed by intervals of relative good health. Second, a significant risk of transmission, which may be sufficient justification to deny services to a person with HIV infection, exists only in very limited situations. Decisions based on the risk of transmission will need to show that an individual poses a significant risk of transmission because of specific actions or behaviors. While programs should have clear procedures for handling HIV-related issues, these procedures should be flexible enough to allow consideration of the relevant facts in each person's case, and to tailor actions to fit individual circumstances.

5. HIV infection must not overshadow other considerations when determining program eligibility or appropriate services.

In most situations, there are any number of qualifications or considerations that guide decisions on program eligibility or service delivery, such as the individual's age, type of impairment(s), degree of severity, and intellectual ability. The fact that the individual also has HIV infection may, or may not, be relevant to these determinations. The developmental and

treatment needs of the individual, and not HIV infection per se, should be the guiding consideration in determining program and service provision.

6. HIV-related concerns must not result in the abandonment of principles of normalization, dignity of risk, and mainstreaming.

The last few decades have seen a slow, but steady movement towards helping individuals with developmental impairments to lead as normal and independent a life as possible. The law has assisted in this effort by recognizing and expanding the rights of persons with disabilities. Yet, the risk of HIV infection has led some to question the advisability of so much freedom. While HIV raises a number of extremely difficult and sensitive issues, especially concerning personal privacy and sexuality, HIV infection should not be used to roll back the clock. The challenge for the DD community is to provide the appropriate education and training that will enable individuals to protect themselves. The concepts of least restrictive alternatives and freedom to make choices -- including decisions involving medical care and sexual relations -- still should guide agency policies and individual program plans.

7. Programs must keep abreast of medical and legal developments.

The law does not exist in a vacuum. It is influenced and shaped by other considerations, one of which is medical knowledge. Many of the cases involving HIV have been determined on the basis of medical facts. Courts rely on the expertise of physicians to assess the risk of transmission in a particular case, as well as to evaluate the person's general health. Based on medical science's determination that HIV infection cannot be spread through casual contact, courts have struck down attempts to deny services or exclude persons with HIV infection based on such a justification.

In making decisions concerning HIV infection, programs should obtain current medical information. Understanding about HIV infection has increased tremendously in a relatively short period, and information that was true several years ago may no longer be valid. It also is advisable to consult with physicians who are experts in the field of HIV infection; they will be in the best position to assess the appropriate responses to a person who has HIV infection. Courts will give greater weight to the medical opinions of an expert that conform to national medical views and may discount opinions that do not conform to these views.

All 50 state legislatures and the District of Columbia have enacted HIV-related statutes covering a wide range of topics, including discrimination, confidentiality, testing and informed consent, reporting, partner notification, school attendance, provider training, quarantine and isolation, health care financing, and HIV education efforts. While the laws discussed in this report generally hold true in most jurisdictions, variations are likely. Furthermore, state legislatures can be expected to enact additional HIV-related statutes in the coming years. Finally, developments in medical treatments for HIV infection will likely affect the application of many laws. In order to ensure compliance with a specific state's laws, programs should obtain legal advice based on the particular facts in a given situation.

FOOTNOTE

1. 42 U.S.C. sec. 6001(5).

II. MEDICAL OVERVIEW

A. General Medical Facts

* Acquired Immunodeficiency Syndrome (AIDS) is caused by the Human Immunodeficiency Virus (HIV) and represents the final stage in a continuum of infection resulting from HIV.

* HIV infection can be divided into three distinct stages: asymptomatic HIV infection, symptomatic HIV infection, and AIDS.

* Although HIV has been detected in certain other body fluids, only blood, semen, vaginal secretions, and, in extremely rare instances, breast milk have been identified as means of transmission of HIV from one person to another.

* Only four routes of HIV transmission have been documented: 1) through unprotected sexual contact, 2) through transfusions of infected blood or blood products, 3) through sharing of intravenous needles, and 4) through congenital or perinatal transmission from a woman to her fetus or newborn, or through breastfeeding.

* Regardless of whether an individual has asymptomatic HIV infection or AIDS, once a person is infected he or she has the potential to transmit HIV to another person through one of the routes listed above.

* HIV cannot be transmitted through "casual" contact, such as living in the same household, attending the same school, or working with a person who has HIV infection.

* Central nervous system involvement becomes one of the major clinical symptoms in infants and children with congenital HIV infection.

B. Medical Overview

1. The Immune System and Acquired Immunodeficiency Syndrome

Acquired Immunodeficiency Syndrome (AIDS) is a disease which impairs the body's immune system. This affects the body's ability to fight disease and leaves a person vulnerable to opportunistic infections; that is, infections that take advantage of the body's inability to resist disease. As of September 1989, 109,167 cases of AIDS had been reported to the Centers for Disease Control (CDC).[1] Of this number, 1,859 were children under the age of 13. The vast

majority of children with HIV infection acquired the virus prior to or during birth. Approximately 18 percent acquired HIV as a result of blood transfusions, before the development of tests capable of screening blood for contamination with HIV.[2] Of those reported to have AIDS, 59 percent of the adults and 54 percent of the children have died.

These numbers do not reflect the true extent of HIV infection. It is estimated that between one and one-half million Americans are currently infected with HIV, and thus likely to develop AIDS over the next decade.[3] The U.S. General Accounting Office estimates that there will be between 300,000 and 480,000 cases of AIDS by the end of 1991.[4] Of this number, the Public Health Service predicts that 3,000 children under the age of 13 will have AIDS, and another 10,000 - 20,000 children will be infected with HIV.[5]

There have been no studies or documentation as to how many of the persons with AIDS also have developmental disabilities. However, the number of adults with developmental impairments who are infected with HIV is thought to be low. The low prevalence of AIDS among persons with developmental disabilities is believed true both for persons living in the community and those living in institutions.[6]

AIDS is caused by the *Human Immunodeficiency Virus (HIV)*, and actually represents the final stage in a continuum of infection resulting from HIV. HIV infection has been divided into three stages. First, individuals have *asymptomatic HIV infection*; they have contracted the virus but do not have any visible symptoms to indicate illness. HIV attacks a specific white blood cell that is essential to the immune system's proper functioning: the T-helper cell lymphocyte. HIV gradually depletes these blood cells, resulting in suppression of the immune system's ability to fight off infections.[7] HIV can have an exceptionally long incubation period -- generally as much as eight to ten years -- before the onset of AIDS.[8] During the asymptomatic period, the infected adult remains healthy, gradually developing symptoms associated with HIV infection. The asymptomatic period is not as long for infants with congenital HIV infection; the majority of these infants will show HIV-related symptoms within the first year.

In the second stage, individuals develop *symptomatic HIV infection*. This phase was formerly referred to as AIDS-related Complex (ARC). During this stage, individuals have various clinical signs, including lymphadenopathy (chronically swollen lymph nodes), weight loss, fever, diarrhea, thrush, general malaise, skin tumors, and other conditions. In children, there also may be unusual pulmonary infections which signal HIV; however, vague general symptoms are more likely, including failure to thrive, developmental delays or loss of previous developmental achievements, diarrhea, and recurrent bacterial infections.[9]

The third phase, AIDS, is also a clinical diagnosis indicated by specific symptoms or diseases identified by the CDC, such as Kaposi's sarcoma and pneumocystis carinii pneumonia.[10] Clinical studies suggest that as many as 50 to 70 percent of persons with AIDS will develop an organic mental disorder, including cognitive impairment, language disorder, movement disorders, psychosis, mood disorders, delirium and dementia. These mental disorders can begin either during the symptomatic phase or once a person has developed AIDS. AIDS-related mental illnesses are included under the umbrella term AIDS dementia complex.[11] At this time, AIDS is believed to be universally fatal.

The progression of HIV infection in children is much more rapid than in adults; however, even in children HIV can have varying rates of progression. While a few infants die within

months of being diagnosed, others can have a slow progression of health problems, while still other children have a long, relatively stable course. Some children with congenital HIV infection have reached eight years of age.[12]

2. Modes of Transmission

HIV has been detected in certain body fluids, including blood, semen, vaginal secretions, breast milk, saliva, tears, cerebrospinal fluid and urine. *However, only blood, semen, vaginal secretions, and, in extremely rare instances, breast milk have been identified as means of transmission of HIV from one person to another.*[13] There is no evidence that transmission of HIV has occurred by contact with any other type of body fluid.[14] In fact, one study suggests that saliva may inhibit transmission of HIV.[15]

Only four routes of HIV transmission have been documented: 1) through unprotected sexual contact, 2) through transfusions or infusions of blood or blood products, 3) through sharing of intravenous needles, and 4) through congenital or perinatal transmission from a woman to her fetus or newborn and, in a few cases, through breastfeeding. While blood has been identified as an agent for transmittal of HIV, transmission can only occur when infected blood comes in contact with an open wound. Skin acts as a barrier to transmission; only if someone has an open wound, or receives an inoculation with HIV-infected blood, is there contact sufficient to risk transmission.[16] Regardless of whether an individual has asymptomatic HIV infection or AIDS, once a person is infected he or she has the potential to transmit HIV to another person through one of the routes mentioned above.

Although the greatest possibility of transmission exists through the modes listed above, the actual probability of exposure can still be quite small. For example, health care workers risk exposure to HIV through accidental needlesticks with blood from HIV-positive individuals. However, the rate of transmission as a result of such accidents has been less than one percent.[17] This does not mean that health care workers, or others who may be exposed to infected blood, should not be concerned or that steps to reduce the risk should not be taken. Rather, the significance of these statistics is to point out that it is difficult to actually contract HIV, even among the methods known to cause transmission.

Public health authorities, following CDC research and recommendations, emphasize that HIV cannot be transmitted through "casual" contact, such as living in the same household, attending the same school, or working with a person who has HIV infection.[18] Studies of the household contacts of persons with HIV infection found no evidence of transmission through nonsexual contacts. Researchers examined a variety of activities, including sharing household items (such as eating utensils, drinking glasses, toothbrushes, towels), sharing household facilities (such as beds, bath/showers, toilets), washing items used by HIV-positive individuals (such as dishes and clothes), and interacting with HIV-positive individuals (such as hugging, kissing, helping someone to bathe or eat).[19]

3. Testing to Detect HIV Antibodies

Currently, two tests are used to isolate HIV antibodies, protein substances in the blood that the body produces in response to the presence of infectious agents, such as HIV. The presence of

a particular antibody is evidence that the individual has been exposed to its corresponding infectious agent. After a person has been infected with HIV, it generally takes from six to twelve weeks before antibodies are produced. The first test is the Enzyme Linked Immunoabsorbent Assay (ELISA) test. An HIV-positive ELISA test must be confirmed with a Western Blot test. These tests were initially developed to screen the blood supply and ensure that no HIV-positive blood was used in transfusions. Although there is still a remote possibility of contracting HIV through blood transfusions, these tests have effectively eliminated blood transfusions as a source of HIV transmission.

The HIV tests are not necessarily accurate indicators of HIV infection in infants under the age of 15 months. The reason for this goes back to the fact that the tests do not detect the actual presence of HIV but only antibodies indicating exposure to HIV. Infants passively acquire their mothers' antibodies through the placenta; thus, a positive HIV test for a six-month old generally indicates that the mother is infected but not necessarily that the baby also has HIV infection. The one exception is if the infant received a blood transfusion; although very rare, transfusion with contaminated blood may still be responsible for HIV infection. In most cases, though, an infant's exposure to HIV will come through his mother. Only 30-50 percent of infants born to HIV-positive mothers will develop HIV infection.[20] A mother's antibodies gradually disappear from the infant, and are usually gone by the time the child reaches 15 months. For example, if a 20-month old child tests positive for HIV antibodies, then it is certain that the child is infected. New tests are being studied that would separately identify an infant's antibodies from the passively acquired maternal antibodies, thus allowing for an earlier, accurate diagnosis of HIV infection in infants. However, these tests are still in the development stage.

4. HIV Infection and the Central Nervous System

Central nervous system involvement becomes one of the major clinical symptoms in infants and children with congenital HIV infection. Estimates suggest that between 78 and 90 percent of all children with HIV infection have some form of central nervous system dysfunction; the incidence of central nervous impairment is significantly greater in children than in adults with HIV infection.[21] It appears that HIV can directly attack the nervous system; some of the opportunistic infections also can affect the nervous system. Congenital HIV infection usually causes developmental delays and a number of cognitive deficits, including mental retardation. Children also exhibit motor function problems, frequently progressive, that can appear to be cerebral palsy. HIV infection appears to be the largest infectious cause of mental retardation and brain damage in children.[22]

5. Medical Treatments for HIV Infection

Much of the HIV research focuses on development of effective treatments. Currently, only zidovudine (AZT) has been approved by the U.S. Food and Drug Administration (FDA) for the treatment of HIV. Recently, the FDA announced that it will permit the distribution of a promising new drug, dideoxyinosine (ddI), despite the fact that it has not completed clinical trials. The drug will be available to individuals with AIDS or symptomatic HIV infection who cannot take AZT because of toxic reactions to that drug, or individuals whose symptoms have not improved while taking AZT.[23]

On October 27, 1989, the Secretary of Health and Human Services announced that AZT would be available to children as an "investigational new drug," meaning that it can be distributed even though it is not yet approved for general licensing.[24] The drug's manufacturer, Burroughs Wellcome Company, has agreed not to charge for the drug when it is prescribed for children until it has been licensed. So far, AZT is the only AIDS-specific treatment approved for children. Clinical trials of AZT, as well as intravenous gamma globulin, have been shown to have a positive effect in modifying the clinical and neurological course of HIV infection in children.[25] One study found that AZT reversed signs of dementia in children, and some gained as many as 30 IQ points in standardized intelligence tests.

FOOTNOTES - MEDICAL OVERVIEW

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III. ANTIDISCRIMINATION STATUTES

A. General Legal Findings

* Persons with developmental disabilities may not be denied their rights and entitlements solely on the basis of their HIV status.

* One's status as HIV-positive triggers the application of federal and most state laws prohibiting discrimination against persons with disabilities.[1]

* Under civil rights laws, a person with developmental disabilities and HIV infection must be individually evaluated to determine if any significant risk of transmission exists that would prevent the person from participating in a particular program.

* Decisions regarding the medical risks of HIV transmission must be consistent with the prevailing national medical opinion of public health officials.

* Given the current medical knowledge about HIV infection, most persons with HIV infection are "otherwise qualified" to participate in public programs and activities.

* Even in the unusual circumstance that HIV infection poses a significant risk of transmission, federal and state antidiscrimination laws generally obligate those who run programs and activities to provide any reasonable accommodations that will eliminate or reduce the risk to acceptable levels.

B. Analysis of Leading Federal and State Statutes Prohibiting Discrimination Against Persons with Disabilities

1. Rehabilitation Act of 1973

The Rehabilitation Act of 1973 contains the primary federal statutory provisions protecting the rights of persons with disabilities.[2] Two provisions under the Rehabilitation Act require affirmative action to increase job opportunities for disabled persons. Section 501 requires federal departments and agencies to implement affirmative action plans to encourage the hiring, placement, and promotion of disabled individuals.[3] Section 503 requires businesses receiving federal contracts of $2,500 or more to take affirmative action to employ and advance qualified individuals with disabilities.[4] The primary antidiscrimination provision, however, is section 504, which prohibits programs and activities that receive federal funding, as well as federal agencies, from discriminating on the basis of handicap.[5] The prohibition extends beyond discrimination in

employment; discrimination in any aspect of a program, including access to benefits and services, are also covered. Most agencies serving persons with developmental disabilities and HIV infection will be covered by section 504, since at least part of their funding, directly or indirectly, is obtained from the federal government. Among the major sources of federal funding triggering section 504 coverage are:

* Developmental Disabilities Assistance and Bill of Rights Act
* Medicaid
* Medicare
* Adoption Assistance and Child Welfare Act
* Education of the Handicapped Act
* Title I of the Elementary and Secondary Education Act
* Rehabilitation Act
* Head Start
* Community Services Block Grant
* Department of Transportation grants
* Department of Housing and Urban Development grants.

Under a recent amendment to section 504 clarifying the scope of coverage, the entire agency or institution is subject to the statute if any component program or activity receives federal financial assistance.[6] This means that the purposes for which funding is received are irrelevant in determining section 504's coverage; the statute applies to the entire agency. Section 504 also will apply to agencies that receive federal funds from intermediate sources. For example, when a state agency contracts with a private agency to provide particular services, and pays for it with federal dollars, the private agency is in receipt of federal funds and must comply with section 504.

a. HIV Infection Is A "Handicap"

The antidiscrimination provisions of the Rehabilitation Act broadly define an "individual with handicaps" to include:

1) persons having a physical or mental impairment that substantially limits one or more major life activities,

2) persons having a record of such an impairment, or

3) persons regarded as having such an impairment.[7]

Infectious diseases, including HIV, are considered "handicaps" protected under section 504. As the Supreme Court noted in *Board of Education of Nassau County, Florida v. Arline*, the infectious nature of a disease cannot be separated from the disease itself; it is merely one

manifestation of the disease.[8] The purpose of section 504 is to provide redress against the public's stereotypes about disease and disability that isolate persons with disabilities and deny them opportunities afforded to the non-disabled. These myths and fears are particularly acute when they involve contagious diseases. To deny section 504's protection to all persons with a contagious or infectious disease would be to allow fear and ignorance to exclude an entire class of persons, regardless of whether, in an individual case, there was an actual risk of transmission to others.

Although courts and legal commentators agree that symptomatic HIV infection qualifies as a "handicap" under section 504,[9] litigation persists on whether asymptomatic infection, without any visible physical or mental symptoms, constitutes a disability. Some have argued that the mere fact of contagiousness cannot qualify as a protected disability. HIV can have a lengthy incubation period; during this time it may cause no visible physical or mental impairments. However, during this time persons infected with the virus have the capability of transmitting it to others.

Congress, the U.S. Dept. of Justice, and courts which have reviewed this issue have concluded that section 504 covers persons with asymptomatic HIV infection.[10] Two alternative arguments support that conclusion. First, even when there are no outward signs of illness, HIV causes abnormalities in the immune system that can qualify as a physical impairment.[11] For example, HIV has a substantial impact on sexual activities and reproduction as a result of the modes of transmission. The fact that these impairments are internal does not negate the physical changes occurring as a result of HIV infection. During this period, HIV infection is similar to other hidden disabilities.

Second, section 504 does not necessarily require that an individual have physical or mental limitations in order to qualify as "handicapped." For purposes of antidiscrimination protection, a person will be considered disabled if a program treats her differently because it regards her as disabled -- the third category of the definition of "handicap."[12] Section 504 is concerned with discriminatory results, regardless of whether the discrimination stems from limitations caused by the impairment or limitations imposed by public reaction to a disease. Public fears and misconceptions about contagiousness can handicap someone in addition to any physical or mental limitations inherent in a disease.

The question of the status of asymptomatic HIV infection may appear irrelevant to persons who have both asymptomatic HIV infection and a developmental disability, since the latter condition clearly would be a disability under the statute. But, for programs that serve only persons with developmental disabilities, a discrimination claim might be based solely on the asymptomatic HIV infection. In this way, the status of asymptomatic HIV infection would be relevant to persons who also have developmental disabilities.[13]

b. Persons with HIV Infection Are Generally Otherwise Qualified

Section 504 only prohibits discrimination against persons with disabilities who are "otherwise qualified" for the benefits or services at issue. Depending on the program, service, or benefit in question, "otherwise qualified" has two distinct but interrelated legal meanings. First, an individual with disabilities must meet legitimate and essential participation or admission requirements. If a program intends to limit admissions by requiring all applicants to meet certain

qualifications, those qualifications must be sufficiently related to the purpose or objective of the program. Since it is unlikely that a requirement that all applicants be HIV-negative will have a relationship to the program or service, such a requirement constitutes a discriminatory qualification for admittance.

The second meaning focuses on the individual's ability to perform or participate in a program, with or without reasonable accommodations. For example, a school or residential program may consider whether its services are appropriate for the client's needs. The mere fact that an applicant has HIV infection will not determine whether the person can successfully participate in a program. To the extent health or disability is ever considered in determining qualification for admission, HIV should be evaluated following the same procedures and standards used for all other health problems.

The "otherwise qualified" language is particularly significant to persons with developmental impairments when it is applied to the possible transmission of contagious or infectious diseases. There must be an individual assessment of specific medical factors to determine whether there is any significant risk of transmission that would prevent an HIV-positive individual from safely participating in a specific program or activity. In evaluating whether an individual is "otherwise qualified" a program must be careful to distinguish between health risks to others and health risks to the individual. While programs may have questions or concerns about the possible risk to the HIV-positive person's health as a result of an impaired immune system, arguably any decisions about the person's health are the responsibility of the person and her physician.

The Supreme Court, in *School Board of Nassau County, Florida v. Arline*, interpreted section 504 to require that any assessment of risk of transmission be based on four factors proposed by the American Medical Association:

1) the nature of the risk (how the disease is transmitted),

2) the duration of the risk (how long is the carrier infectious),

3) the severity of the risk (what is the potential harm to third parties), and

4) the probability that the disease will be transmitted and will cause varying degrees of harm.[14]

A determination of each of these points must be consistent with the prevailing national medical opinion of public health officials. After weighing these factors, a program must find a signficant risk of transmission in order to justify its determination that an HIV-positive individual is not "otherwise qualified" for services or benefits.

Applying this standard to HIV infection, courts have prohibited efforts to exclude or segregate individuals because the risk of transmission is insignificant or nonexistent in public and familial settings, e.g., schools, workplace, health care facilities.[15] In most cases, the fourth factor -- the probability of transmission -- will be determinative. The limited modes of transmitting HIV make casual social contact safe. While HIV has been isolated in a number of body fluids, such as saliva, tears, urine, feces, sweat, nasal secretions, vomitus and cerebrospinal fluid, *only blood, semen, vaginal secretions, and breast milk have been found to transmit the virus.*[16] Studies of the routine contact between persons with HIV and their families have

consistently found that HIV is not spread by sneezing, coughing, breathing, hugging, sharing eating and drinking utensils, using the same toilet facilities, or other form of nonsexual contact.[17] Since the risk of transmission of HIV is limited to four body fluids, the possibility of exposure to any other fluids does not justify discrimination against a person with HIV infection.

The "otherwise qualified" analysis is not limited to questions concerning the risk of HIV transmission. Regardless of the disability, each person is entitled to an individualized review of their qualifications for a specific program. In most situations, determining whether an individual with a developmental disability is "otherwise qualified" for admission or participation in a program will involve considerations unrelated to HIV infection.

c. Programs Must Provide Reasonable Accommodations

Where a significant risk of transmission from blood, semen, or vaginal secretions were to be found to exist, section 504 requires a program to seek "reasonable accommodations" to eliminate or diminish the risk. A reasonable accommodation is any adaptation, modification, or service that addresses the abilities of a person in order to permit participation in a particular opportunity. The need for any accommodation, or the type of accommodation necessary, will vary depending on the context and the individual. It is important to remember that accommodations are required not merely to lessen the risk of HIV transmission, but to address any limitations resulting from a developmental impairment. For the person with a developmental disability and HIV infection, accommodations are more likely to be needed because the person's health requires program modifications, or her developmental impairment requires adjustment of certain program elements or procedures to enable her to participate.

At the same time, there are limitations on the extent to which a program must make such accommodations. If an accommodation changes the *fundamental* or essential nature of a program, then it is considered inherently unreasonable and not required by section 504. For example, a program need not alter its reasonable admissions or eligibility criteria, or significantly alter its curriculum or services, if such changes would prevent the program from achieving its major purpose. The law draws a distinction between changes in methods used to accomplish program objectives, which are required, and changes that substantially alter a program's objectives, which are not.

Courts and administrative review agencies will examine closely claims that a proposed accommodation fundamentally changes a program. The mere fact that established policies, job assignments, or a child's curriculum needs to be adjusted is not necessarily a fundamental change. Eligibility criteria which intentionally or unintentionally exclude persons with HIV infection will face close scrutiny to determine whether they reasonably relate to the objectives of the program. Although no courts have directly addressed the types of accommodations required for persons with HIV infection, courts have noted the use of routine infection control procedures, such as cleaning soiled surfaces and washing hands, as a way of eliminating or diminishing any risk of transmission.[18]

Two other limitations on the duty to provide accommodations involve the cost and administrative burden of an accommodation. The mere fact that an accommodation will entail some cost to implement does not make it an unreasonable accommodation. The reasonableness of the cost will depend on several factors, including the size of the program and its budget, and

the number of persons who will benefit. Nor is increased administrative work sufficient to preclude a particular accommodation. An argument that implementation of universal precautions is unreasonable due to cost or administrative burden is likely to fail. The Centers for Disease Control (CDC) recommend implementing infection control procedures in many settings -- including health care facilities, schools, day care, and foster care programs -- for public health purposes.[19] Given the public health mandate to implement such measures, and their minimal expense, such precautions would be upheld as a reasonable accommodation.

Moreover, the fact that one possible accommodation is too onerous does not negate the requirement. Other possible accommodations must be considered and implemented if reasonable.

2. Education for All Handicapped Children Act (P.L. 94-142)

The Education for All Handicapped Children Act requires states to provide a public education to all children with disabilities, regardless of the severity of the disability, in order to receive federal financial assistance for special education programs.[20] The statute requires states to guarantee to each child and his parents certain rights, including:

* a free, appropriate public education (in some instances this may include placement at a private school at public expense)

* individualized assessment of each child's educational needs, specified in an Individualized Education Program (IEP)

* parent/guardian participation in decisions about the child's educational needs and approval of educational plans

* appeal by the parent/guardian of any decision through detailed due process procedures

* children be educated in the "least restrictive environment;" in other words, in the most normal education setting possible.[21]

In contrast with section 504 of the Rehabilitation Act, P.L. 94-142 has been interpreted to require that students bringing complaints under the statute fully exhaust administrative remedies before filing a lawsuit.[22]

a. HIV Infection May Qualify As a "Handicap"

The definition of "handicap" in P.L. 94-142 is more restrictive than in section 504. This is not surprising given that P.L. 94-142 has a more limited purpose than section 504; the latter is a general antidiscrimination statute applicable in many types of programs and institutions. P.L. 94-142, however, seeks to guarantee a free, appropriate public education for children whose disabilities create the need for special education services or programs.

The statute employs a two-part definition of "handicapped children." First, the child must have a disability, which the statute defines as any of the following: "mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed,

orthopedically impaired, or other health impaired children, or children with specific learning disabilities." Second, the child must require "special education and related services" as a result of having one of the above-mentioned impairments.[23]

Most children with symptomatic HIV infection, including AIDS, will meet this definition of "handicapped." First, the child may have certain impairments listed above caused by HIV infection. Any of their symptoms might qualify as one of the "other impairments" that can constitute a disability. Second, these impairments, many of them developmental in nature, will generally necessitate additional educational services.

Children with asymptomatic HIV infection might also qualify as handicapped if they have developmental impairments unrelated to the HIV, provided the impairments necessitate special education services.[24] But, children who only have asymptomatic HIV infection probably will not meet the statutory definition; these children are unlikely to require special education services precisely because they have not yet developed any symptoms.[25] If these children later develop symptoms, they would have to be reevaluated to determine if there was a need for special education services.

Even if an asymptomatic HIV child is not considered to have a "handicap" under P.L. 94-142, the child's right to a public education will be protected under section 504. In enacting the Handicapped Children's Protection Act of 1986, Congress affirmed that P.L. 94-142 does not negate or preempt section 504 rights.[26] As previously discussed, the overwhelming legal opinion is that section 504's broad definition of "handicap" encompasses individuals with asymptomatic HIV infection. Courts have held that children with asymptomatic HIV infection were not "handicapped" under P.L. 94-142 while finding these same children "handicapped" under section 504.[27] Since these children seek access to the classroom, and not special education services, section 504 prohibits education officials from refusing them admission, except if they can prove that the child poses a significant risk of transmission to others that cannot be eliminated with reasonable accommodations.[28]

b. Educational Placement of Children with HIV Infection Requiring Special Education Services

Most children with congenital HIV infection will be considered "handicapped" under both section 504 and P.L. 94-142. The Eleventh Circuit, in *Martinez v. School Board of Hillsborough County, Florida,* laid out a step-by-step approach for determining the appropriate educational placement for a child with HIV infection who requires special education services, in accordance with the requirements of the two statutes.[29] First, under P.L. 94-142, a school must determine the most appropriate educational placement based solely on the child's educational needs. Second, the school may then consider whether the child is "otherwise qualified" under section 504 to be educated in the chosen setting. Using the four-factor *Arline* test, the school may determine whether there is any significant risk that would make the educational placement inappropriate. Third, if a significant risk is found, the school must consider whether any reasonable accommodations could reduce the risk, thus making the child "otherwise qualified" for that placement. Each potential accommodation must be assessed as to its fulfillment of P.L. 94-142's requirement that a child be educated in the least restrictive environment.

3. Fair Housing Amendments Act of 1988

Congress extended existing housing discrimination protections to disabled persons, including those with HIV infection, in the amendments to the Fair Housing Act of 1968. The Fair Housing Amendments Act of 1988 (FHAA) added persons with disabilities to the list of protected classes, prohibiting discrimination in a variety of housing transactions, including (but not limited to):

* sale or rental of a dwelling
* terms, conditions, or privileges of a sale or rental
* housing loans and other financial assistance
* brokerage and appraising services.[30]

In addition to section 504, which applies to federally assisted housing, the FHAA applies to housing or rental transactions regardless of whether federal funding is involved. Since most private real estate transactions do not involve federal funds, the FHAA provides a significant expansion of civil rights protection available to persons with disabilities.

a. HIV Infection Is A "Handicap"

The statute adopts section 504's broad definition of "handicap" which, as discussed above, encompasses persons with HIV infection. Congress, aware of debate on the status of asymptomatic HIV infection as a handicap under section 504, stated in the report explaining the purpose and coverage under the FHAA that asymptomatic infection with HIV constitutes a handicap.[31] The Dept. of Housing and Urban Development (HUD) regulations implementing the FHAA specifically include HIV infection under the list of "physical or mental impairments" constituting a handicap.[32]

b. Discrimination in Housing Based on HIV Status Generally Prohibited

Congress also chose to incorporate the Supreme Court's standard on risk analysis in *School Board of Nassau County, Florida v. Arline*, requiring individual assessment of whether disabled individuals, including those with an infectious or contagious disease, present a direct threat to the health of others.[33] The FHAA does not require that a dwelling be made available to a person whose tenancy would "constitute a direct threat to the health or safety of other individuals or whose tenancy would result in substantial physical damage to the property of others."[34] This is a strict standard requiring the property owner to establish a nexus between the individual's tenancy and the alleged direct threat, resulting in a significant risk of transmission to others sufficient to justify denying housing or housing services to the individual.

Just as the FHAA incorporates the risk analysis of section 504, it also incorporates section 504's requirement that reasonable accommodation be provided to eliminate or reduce any substantial risk. The statute defines discrimination as a refusal to make reasonable accommodations in rules, policies, practices, or services.[35] The House Judiciary Report states that by incorporating the section 504/*Arline* analysis, it was requiring property managers to provide reasonable accommodations.[36]

Housing discrimination can affect more than just the disabled person; family members, other potential roommates, or visitors may be denied housing opportunities because they wish to live or associate with a disabled person. The FHAA prohibits discrimination against non-disabled persons solely because they will live with or visit a disabled person.[37] Among the groups protected are parents, friends, spouses, roommates, and children, as well as counselors and staff who reside in group homes.[38]

For many persons with disabilities, independent community living requires some form of group home arrangement. Yet, through a variety of means -- restrictive covenants, zoning laws, land use or health and safety regulations -- communities have prevented, or made it exceedingly difficult, to establish group homes for persons with developmental disabilities. Given public fear and misconceptions about HIV infection, resulting in community opposition to housing for persons with HIV infection, individuals with developmental disabilities and HIV infection may have an even greater difficulty finding appropriate housing.[39]

The FHAA offers assistance in opposing these exclusionary measures. Although the statute does not specifically prohibit exclusionary measures, the House Judiciary Committee Report explains its intent is to prohibit use of these measures in a discriminatory way.[40] Furthermore, the Report specifies congressional intent to prohibit judicial enforcement of any land use regulations, covenants and conditions which have the effect of limiting the housing opportunities of people with disabilities.[41]

Since the U.S. Dept. of Justice, and not HUD, has the responsibility to enforce the FHAA in the context of land use regulations, the HUD regulations do not address this issue. However, the Dept. of Justice has taken the position that a zoning board violated the FHAA by denying a special use permit to a sponsor of a group home for tenants with mental disabilities.[42]

4. State Laws Protecting Persons with Disabilities

All fifty states, plus the District of Columbia, have enacted antidiscrimination protection for persons with disabilities. These statutes can be an important source of protection for persons with developmental disabilities and HIV infection; these laws may offer protection in programs and services not covered by one of the federal antidiscrimination statutes. For example, some state statutes protect disabled persons from discrimination by private employers, which is illegal under section 504 only if the employer receives federal funding.[43] While many state statutes supplement protections available under section 504, requirements to exhaust administrative remedies before filing a lawsuit often delays effective action for several years due to an administrative backlog of cases.[44]

a. HIV Infection Generally Qualifies As a "Handicap"

As of January 1, 1989, 24 states and the District of Columbia had formally extended some or all of their antidiscrimination laws that protect persons with disabilities to persons with HIV infection.[45] Nineteen of these states also protect persons perceived to be HIV infected; in addition, Texas covers persons perceived to have AIDS. In three states, persons with infectious or communicable diseases are specifically excluded from the definition of handicap, thus making it almost impossible to cover persons with HIV infection under these statutes.[46] The status of

persons with HIV infection under the remaining statutes has not been formally determined, but it is likely most of these states would follow the same approach as their sister states.

States have used a variety of means to extend the protection of their antidiscrimination statutes to persons with HIV infection. Some states -- including Florida, Iowa, and Washington -- amended their statutes to specifically include HIV infection.[47] But only seven states extended coverage through legislative action.[48] In most states, either the executive agency responsible for enforcing the antidiscrimination law, such as the civil or human rights commission, or the state attorney general issued a policy interpretation that HIV infection qualifies as a "handicap."[49] In a few states, courts have interpreted state disability antidiscrimination statutes, including those in California, New York, and Massachusetts, to cover persons with HIV infection or AIDS.[50]

b. Programs Covered by State Statutes

The extent of protection offered by these laws varies, based on the programs and activities subject to these statutes. Some statutes apply only to discrimination in state agencies.[51] Other states model their statutes after section 504, linking coverage to receipt of state funding.[52] Another group of statutes prohibit discrimination in certain areas, such as employment, housing, or public accommodation, regardless of whether state funding is involved.[53] Persons with HIV or AIDS have successfully used these statutes in bringing discrimination claims against employers and landlords.[54] However, the full extent of coverage in any of these areas may be uncertain. For example, there have been several lawsuits challenging state antidiscrimination laws interpreted to define medical offices as public accommodations.[55] Given these variations, a person with HIV infection and a developmental disability would need to check her state's laws to see whether a particular agency, program, activity or service is covered.

As of January 1, 1989, 20 states had enacted HIV/AIDS-specific antidiscrimination protection, generally prohibiting discrimination in employment, housing, or both. Fourteen of these states have also extended their general disability antidiscrimination statutes to cover persons with HIV infection and/or AIDS.[56] States often supplement existing antidiscrimination protections with HIV-specific legislation in order to rectify any gaps in coverage. Some HIV-specific statutes prohibit employers from requiring individuals to disclose HIV test-related information as a condition of hiring, promotion, or continued employment.[57] New Mexico, Texas, and Washington laws permit employee testing only if the employer can prove that the absence of HIV infection is a "bona fide occupational qualification."[58] New Hampshire adopted a statute prohibiting eviction of a tenant solely because the person has AIDS.[59]

A few states have enacted statutes that extend protection against discrimination to education and health care. For example, Montana, Iowa, New Jersey, Rhode Island and West Virginia statutes forbid health facilities from denying admission or services solely because a person is HIV-positive.[60] Maryland's statute took a unique approach to devising penalties for discrimination; the legislature amended existing licensure laws to authorize denial, suspension, or revocation of a license if the professional denies service to someone because the individual is HIV-positive. The law covers over 20 health-related professions, including physicians, nurses, dentists, social workers, physical therapists, occupational therapists, and speech-language pathologists.[61] The legislatures in Nebraska and Virginia directed the departments with responsibilities for serving persons with mental retardation and other developmental disabilities

to review their regulations and policies to ensure that there is no discrimination against persons with HIV infection.[62]

c. Persons with Disabilities Must Be Otherwise Qualified

Although statutes may use different language, most statutes contain provisions, or have been interpreted to require, that a person with disabilities be "otherwise qualified" for a program or service.[63] Similarly, a majority of these statutes specifically impose or through interpretation require reasonable accommodations be provided.[64] However, relatively few cases have examined the extent of the duty to provide reasonable accommodations. Absent any statutory language explaining or limiting the duty to accommodate, state administrative agencies and courts can be expected to rely heavily on federal caselaw.[65]

5. The Americans with Disabilities Act of 1989

Congress is currently considering enactment of legislation that would greatly expand the federal protection available to persons with disabilities, including those with HIV infection. The Americans with Disabilities Act of 1989 (ADA) would prohibit discrimination on the basis of disability in the public and private sector in the areas of employment, public accommodations, public service, transportation, and telecommunications.[66] The description that follows is based on the bill approved by the U.S. Senate on September 7, 1989. The legislation is currently being reviewed by several committees of the House of Representatives, and thus could undergo changes before final passage.

In contrast with section 504, the ADA's requirements would apply to programs and activities regardless of whether they received federal funding. The ADA uses section 504's definition of "handicap;" consequently, persons with HIV infection are covered. The Senate Report accompanying the legislation states that persons with HIV are protected by the ADA. The legislation also incorporates section 504's legal framework to assess whether an individual is "otherwise qualified" to participate in a program. This means that a person with HIV infection is not "otherwise qualified" if a program can prove that she poses a significant risk of transmitting the infection, and that this risk cannot be eliminated through reasonable accommodations.

The ADA also is modelled after other civil rights statutes, including Titles VI and VII of the Civil Rights Act of 1964.[67] During the first two years after enactment, the ADA would apply to all employers with 25 or more employees; thereafter, the number goes down to 15 employees. The legislation lists examples of what constitutes employment discrimination, and codifies the requirement that "reasonable accommodations" be provided, specifying types of accommodation that are reasonable. However, any accommodation that poses an "undue hardship" would not be reasonable.

The legislation also extends coverage to all activities of state and local governments, including public transportation, such as bus or rail service. The ADA includes specific timetables and requirements for providing non-discriminatory transportation services.

Public accommodations and services operated by private entities are prohibited from discriminating against persons with disabilities. These accommodations include: restaurants; hotels; doctors' offices; retail stores such as grocery or clothing stores; day care centers; and

places of entertainment, such as movie theaters and sports arenas. These establishments must provide all accommodations that are "readily achievable." The legislation also specifies when structural changes must be made to allow access to persons with disabilities.

C. Application of Discrimination Laws

1. Rehabilitation Act (section 504) and State Antidiscrimination Statutes

Since the answer to many of the questions that follow are the same or similar under both federal and state antidiscrimination statutes, this section considers both sets of statutes together. However, due to variations in state laws, you should consult your state's antidiscrimination statute to determine how it answers these questions.

(a) May a program deny services, benefits, or employment to a person with a developmental disability solely because that person also has *AIDS*?

Services, benefits, or employment cannot be denied to persons with AIDS and a developmental disability based solely on fear or concerns about possible transmission of HIV. AIDS, as well as other mental and physical symptomatic conditions caused by HIV, qualify as disabilities under section 504, and most state antidiscrimination statutes, because they substantially limit major life activities. Blanket exclusions will be judicially suspect since they do not allow for individual evaluation of each person's medical condition and other relevant factors.[68] While exclusion based solely on AIDS is considered discrimination under the law, the individual must still meet reasonable and legitimate qualifications applied to all other applicants.

(b) May a program deny services, benefits, or employment to a person with a developmental disability if that person also has *asymptomatic HIV infection*?

Services, benefits, or employment cannot be denied to a person with a developmental disability and asymptomatic HIV infection solely because of fear or concerns about possible transmission of HIV. Section 504 includes persons with asymptomatic HIV infection; half the states have taken steps to make clear that their statutes extend to persons with asymptomatic HIV infection.

In *Kohl by Kohl v. Woodhaven Learning Center*, a residential facility and a habilitation program for persons with disabilities denied admission to a mentally retarded man with active hepatitis B, a contagious disease transmitted in a similar manner as HIV.[69] When Kohl sued under section 504, Woodhaven claimed that he was not "handicapped" under the law because the hepatitis had caused no physical or mental impairments; Kohl was merely a carrier and that did not constitute a handicap under section 504. The Eighth Circuit Court of Appeals disagreed, and held that Kohl's hepatitis qualified as a "handicap" under section 504.

(c) May a program deny services or benefits to an infant known to be *at risk* of having HIV infection, but not yet positively diagnosed?

Under section 504, a program may not deny services or benefits to an infant because it regards him as being at risk of having HIV infection. If an infant showed certain symptoms associated with HIV infection, and the mother was known to be HIV-positive, the infant would be considered at risk of having HIV infection. However, a conclusive diagnosis may be difficult for infants under the age of 16 months.[70] In this situation, a program cannot deny services to infants solely on the suspicion that they have HIV infection; section 504 prohibits discrimination based on the perception that an individual has a handicap.

Many state statutes do not extend coverage to persons perceived to have a disability, limiting coverage to persons with actual conditions. This makes it questionable whether an infant known to be at risk of HIV infection would be protected from discrimination. However, some of these states, like Florida, have rectified this problem by enacting new statutes that specifically cover individuals perceived to have HIV infection. The majority of state disability antidiscrimination statutes do extend coverage to persons perceived to have a disability, and thus would protect an infant known to be at risk of HIV infection.

(d) Can a program deny services or placement to a person with a developmental disability and HIV infection because of concerns that certain behaviors caused or exacerbated by the developmental impairment increase the risk of transmission?

A program must individually assess each person to determine whether he is "otherwise qualified" to receive services. Included in this evaluation is a determination of whether the individual presents a significant risk of transmission sufficient to justify a denial of services. Four factors must be considered: the nature, duration, and severity of the risk, and the probability of transmission. The behaviors must have a direct link with the three identified modes of transmission -- blood, semen, vaginal secretions, and breast milk. Behaviors involving other types of body fluids would not justify refusing services to someone. For example, a program cannot deny services to an HIV-positive individual who drools or bites, based on concerns about possible HIV transmission to staff or other clients, because saliva is not one of the modes of transmission. Even aggressive behaviors that might result in exposure to blood will usually not constitute a significant risk, both because the probability of transmission is low and use of routine precautions will help ameliorate any risks. [See Question (f)] All programs may properly prohibit clients from engaging in intravenous drug use; programs that are not equipped to offer drug rehabilitation services to current drug users can consider whether their programs are appropriate for an individual with this problem.

The fact that an individual has a developmental impairment does not, per se, create a significant risk of transmission. Identification of a developmental impairment is not synonymous with certain risky behaviors. A program must evaluate each person to determine whether he presents particular behaviors or characteristics, caused or exacerbated by a developmental impairment, which increase the risk of transmission.

Even if a significant risk of infection is found, the program must review all reasonable accommodations that might eliminate or minimize the risk and allow the individual to be served.

(e) Can a program deny services or placement to a client with developmental disabilities and HIV infection because of concerns that the client's unprotected sexual activities increase the risk of transmission?

This question is of greatest concern to residential programs, since sexual activities can properly be prohibited in all other types of programs and settings. A distinction should also be drawn between consenting and non-consenting sexual activity. The latter is a crime, and programs should provide training and counseling to clients on how to avoid sexual exploitation. An applicant or client who engages in aggressive sexual behavior, regardless of whether he or she is HIV-positive, presents a different set of questions about whether a particular residential program can provide the services needed while protecting other clients from sexual attacks.

Residential programs probably cannot prohibit consenting sexual activity between adults, and the mere fact that clients are sexually active does not justify exclusion from programs to which they otherwise would be admitted. However, there are legitimate concerns about the risk of HIV transmission. As always, a program should first evaluate whether the program offers appropriate services for the client's needs. Only then should the program consider whether the client's HIV infection poses a significant risk of infection. Programs must individually assess each client to determine:

1) the client's likelihood of engaging in sexual activities,

2) the client's understanding that certain behaviors and activities carry a risk of transmitting HIV,

3) the client's ability and motivation to cooperate voluntarily with infection control measures (understanding and using protected sexual practices), the client's access to the means of practicing protective measures (the availability of condoms), and the client's ability to control high risk behavior and practice safe sex.[71]

If the HIV-positive client is sexually active, understands his or her condition, the risks presented by unprotected sexual activity, the need to practice safe sex, and if the client has the ability to use safe sexual practices, then a residential program probably cannot justify exclusion based solely on risk of HIV transmission. If a sexually active HIV-positive client does not understand his or her condition, the risks of transmission, or the need to practice safe sex, or lacks the ability or motivation to use safe sexual practices, the program must consider what steps it could take to change the client's risky behaviors. Again, these steps could include education, training, and counseling, focusing on sexuality, methods of preventing sexually transmitted diseases, and access to condoms. For clients who either are unable or unwilling to engage in safer sexual practices, increased supervision or separate sleeping arrangements may be appropriate. If a program has implemented all reasonable accommodations and given the individual time to change, but the individual remains unable or unwilling to alter his or her risky behavior to avoid transmitting HIV to a sexual partner, then denial ofservices would be a legally appropriate measure. However, programs should take steps to find a more appropriate service or program for the client.

(f) What constitutes a reasonable accommodation for a person with a developmental disability and HIV infection?

Given public health recommendations to implement infection control procedures as effective means of preventing transmission of blood-borne diseases, these measures would, at a minimum, be considered reasonable accommodations. These procedures include:

* wearing gloves, masks, gowns, and other protective shields if exposure to blood is anticipated

* washing hands or other body parts immediately after exposure to blood

* washing immediately any surfaces exposed to blood with a mixture of water and bleach.[72]

Other possible accommodations depend on the type of risk that a program is seeking to ameliorate. For example, concern about the possible transmission of HIV through unsafe sexual practices may be alleviated by providing an appropriate sexual and HIV educational curriculum. Another possible alternative may be increased supervision.

Accommodations may also be needed if the client or patient has secondary infections resulting from HIV, such as tuberculosis. Even though there probably will not be a significant risk of transmitting HIV, there may be a significant risk of transmitting a secondary infection if it is highly contagious. Accommodations may be required to prevent transmission of these diseases and infections. The form of accommodation will depend on the type of risk.

It is important to remember that no single accommodation will be appropriate for all individuals with developmental disabilities and HIV infection. Since transmission of HIV is linked to engaging in certain unsafe behaviors, a careful evaluation of behaviors, and the possibility that they may lead to transmission, would be necessary. Based on this review, program staff could determine appropriate accommodations. Also note that accommodations are required only if a particular person poses a significant risk of transmission; the mere fact that a person has a developmental impairment and HIV infection does not necessarily mean that any accommodations will be required.

(g) To what extent must a program alter its services to provide reasonable accommodations to someone with a developmental disability and HIV infection?

Section 504 does not require fundamental alterations in a program. A residential or day program that serves only adults with mild mental retardation needing minimal supervision would not be required to provide services for an adult with profound mental retardation simply because he also happens to have HIV infection. However, if this same program rejected an adult with mild mental retardation and HIV who met all admissions criteria, then there would be a question of discrimination based on HIV infection.

The critical question for any program is whether it would admit the individual or provide her with services if she only had a developmental disability. If the answer is yes, then the HIV infection, in most cases, probably will not be a barrier to admission or provision of services. In

order to avoid discriminatory decisionmaking, a program should engage in a three-step review process when considering the admission of a person with a developmental impairment and HIV infection:

1) Is this program appropriate for the developmental needs of this individual?

2) Does the individual present a significant risk of infection?

3) If the individual presents a significant risk, are there reasonable accommodations to minimize the risk, making the person eligible for the program?[73]

(h) Can a program rely on the medical opinion of its staff physicians in determining possible risk of transmission?

The medical opinion of staff physicians will probably be struck down if it is inconsistent with the prevailing national medical opinion of public health authorities. The Supreme Court, in *School Board of Nassau County, Florida v. Arline*, required that risk analysis be based on reasonable medical judgments of public health officials, but specifically left open the question of relying on the opinions of private medical personnel.[74] Clearly, private medical opinions must be consistent with current medical and scientific data. If a physician believes that a significant risk exists, that opinion should be documented with public health materials citing the risks caused by certain modes of transmission. A program cannot justify denial of services based on a staff physician's report of a theoretical possibility of transmission.

While courts may give greater deference to public health authorities in assessing risk of transmission, they may give greater deference to staff opinions regarding issues of reasonable accommodation.[75] However, courts may scrutinize the basis for the staff's opinion, to determine if any bias in favor of the employer's position influenced the opinion.[76]

Depending on the type of program or service, staff recommendations would need to reflect expertise in various areas, such as HIV infection, developmental disabilities, education, vocational training or employment. It is important that a staff member be qualified to give recommendations regarding specific issues. For example, a parent may register her child, who has a developmental disability and HIV infection, to be enrolled in school. The school may consult with a physician who has expertise in HIV infection to provide guidance on the risk of transmission.[77] However, the physician's expertise may not extend to issues concerning the child's developmental disability; nor would the physician's expertise ordinarily extend to the educational needs of the child. Given the need for expertise in a number of areas, programs might want to consider forming multi-disciplinary teams which, at a minimum, should include persons with expertise in HIV and other infectious diseases, developmental disabilities, the law, and other disciplines as appropriate. However, programs should be aware that employing these teams could raise confidentiality issues, depending on whether identifying information is provided. (For a discussion of confidentiality-related issues, see Chapter V.)

(i) Can a day care center or school deny admission to a child with a developmental disability and HIV infection because the child bites or is not toilet trained?

The fact that a child bites or is not toilet trained, by itself, does not increase the risk of infection since saliva, urine and feces are not considered modes of transmission. With more time and study, researchers have refined initial views on transmission, which will have a significant impact on questions regarding the risk posed by a particular child. For example, initial public health recommendations advised caution around a variety of body fluids.[78] However, these recommendations have been revised to reflect current information showing that the means of transmission is limited to four body fluids -- blood, semen, breast milk, and vaginal secretions.[79] In response to these changes, day care programs and state agencies are changing their policies. For example, the Massachusetts Dept. of Public Health previously recommended that children under the age of four with HIV infection be excluded from day care programs based on concerns about transmission from drooling or bodily wastes.[80] Amending this policy in June 1989, the Department now recommends that these children be admitted to day care programs unless: 1) they have weeping or bloody skin or mouth sores that cannot be covered or controlled with medication; 2) engage in biting "of an unusual frequency or severity" accompanied by actual transfer of blood; or 3) have bloody diarrhea. These exceptions to admission are not unique to HIV infection; the Department's guidelines note that these restrictions apply to any child in an early childhood setting.

Biting is not considered to present a significant risk of transmission because saliva is not a mode of transmission. Biting may be a cause for concern if there is blood mixed in with the saliva, and if the bite breaks the other person's skin. In a case involving a child with HIV infection who was excluded from kindergarten after biting another child, a federal district court ordered the child readmitted. The court found that the "overwhelming weight of medical evidence is that the AIDS virus is not transmitted by human bites, even bites that break the skin;" the court held that a theoretical risk of transmission was insufficient to bar the child from attending kindergarten.[81] Any child with aggressive behaviors who repeatedly bites requires an appropriate educational program addressing this behavior.

Program policies that merely use the term "body fluids," or specify a comprehensive list of such fluids encompassing more than the four noted above, no longer are based on current medical evidence sufficient to justify different treatment of a person with HIV infection. Programs should keep abreast of current medical opinion regarding transmission, and update policies as needed.

(j) Given that medical knowledge about HIV infection has changed over the last few years, how can a program make decisions based on medical opinions that may change again?

For some time now, evidence has been consistent about the causes of HIV transmission. Based on current medical evidence, courts have consistently found that persons with HIV infection can be admitted to programs because there is little or no risk of transmission through casual social contact. The most significant medical changes that are occurring involve the treatments available for HIV-related conditions, as well as HIV itself.

The law requires that decisionmaking involving HIV-related issues be based on the prevailing national medical opinion of public health experts at the time of the decision. That is why it is important for programs to document the basis of their decisions, especially those that deny services to a person based on his HIV infection. Courts closely examine the information used to support a decision, and compare it with objective medical evidence available during the period when the decision was made, to ensure that the decision is supported by prevailing medical opinion and not speculative or irrational beliefs.[82]

2. Education for All Handicapped Children Act (P.L. 94-142)

(a) May a school refuse to admit a child with a developmental disability and HIV infection because of the risk to the child's health from an impaired immune system?

Decisions regarding the possible risk to a child's health from exposure to others in a school setting largely are the responsibility of the child's parents and his physician.[83] Regardless of whether a child with HIV infection is present, schools have established standard procedures requiring students with highly contagious or infectious diseases, such as chicken pox, to remain out of school until the risk of transmission is passed. So long as these procedures are followed, then a school has fulfilled its responsibility to all students, including the child with HIV infection.

Excluding the child from school would not guarantee her safety or long life; the risk to the child's health exists from exposure to anyone in any setting. Offsetting any risk to the child's health are the benefits to the child's emotional and educational development in attending school with other children. Courts have refused to exclude children from school based on a school's concern for the risks to the child with HIV infection, and instead have upheld the right of parents, with the advice of their child's physician, to have their child attend school.[84]

(b) Can a school limit the placement options of a child with a developmental disability, based on concerns about HIV infection?

A school must follow the procedural requirements of P.L. 94-142, as well as section 504, in determining the appropriate educational placement of a child. This entails a three-step process of evaluation:

1) determination of the appropriate placement based on the educational needs of the child,

2) determination of whether the child poses a significant risk of transmission,

3) if there is a significant risk, determination of whether any reasonable accommodations are possible, consistent with the least restrictive mandate.

Applying this test to a seven-year-old child with mental retardation and AIDS, a federal court found that the child was qualified to be in a class with other children.[85] School authorities and the child's mother agreed that this was the most appropriate educational placement. The fact that the child was not completely toilet trained, and sometimes sucked her fingers, did not create a significant risk of transmission sufficient to exclude the child from the classroom.

Courts have refused to uphold efforts to exclude children with developmental disabilities and infectious diseases based on remote or theoretical risks of transmission.[86] Instead, a school must establish a nexus between a particular behavior or characteristic, and a mode of transmission sufficient to create a significant risk. Courts have carefully reviewed a child's developmental level to determine whether a significant risk of transmission exists. For example, an Illinois appeals court upheld an order to "mainstream" a teenager with a mental disability who also was a carrier of hepatitis B. The teenager understood her medical condition and the potential risks. On her own inititative she took care with her personal hygiene; there was no evidence that she ever attempted to attack someone else or exhibited any other types of behavioral problems that could lead to transmission.[87]

Efforts to isolate children with infectious diseases, or limit them to homebound instruction, have been overturned by courts because of the harm such decisions inflict on a child's social and emotional development. One of the primary goals of classroom education is the socialization process that occurs through interaction with other children. Homebound instruction, or limited access to peers, interferes with this process and can have an adverse impact on the child.[88] Unless a significant risk of transmission exists, and no reasonable accommodations can be provided, courts will not sanction such isolation.

3. Fair Housing Amendments Act of 1988 (FHAA)

(a) Can a city deny a zoning permit to a group home for persons with developmental disabilities because of concerns that some or all residents also have HIV infection?

Congress, concerned about continuing public hostility to the establishment of group homes for persons with disabilities, stated its intention that the FHAA be used to prohibit exclusionary zoning practices, including health and safety regulations, land-use and zoning regulations, and restrictive covenants that prevent people with disabilities from living in group homes.[89] The law makes it unlawful to adopt or enforce a regulation that excludes persons with disabilities or restricts them from living in group homes. Furthermore, the FHAA allows group home providers and other community residence operators to challenge exclusionary zoning practices. Since persons with developmental disabilities and HIV infection are considered "handicapped" under the FHAA, they have the full protection of the statute.[90] Exclusionary zoning practices have long been a target under the parent statute, the Fair Housing Act; courts have struck down a variety of land-use and zoning rules that have the effect of discriminating on the basis of race, reasoning that these practices perpetuate the segregation the statute intends to eliminate.[91]

As of September 1989, one federal court and at least one state court have issued decisions interpreting the FHAA with regard to individuals with disabilities. In *Baxter v. Belleville, Illinois*, the zoning board denied the plaintiff a special use permit to use a single family house as a hospice for people with AIDS.[92] The court held that the zoning board's action violated the FHAA and ordered the board to issue the permit. The court permitted the zoning board to establish reasonable conditions with regard to the disposal of waste and the non-admission of current illegal drug users as residents. As the court explained:

> The court is cognizant of the strong public concern with the transmission of a fatal disease for which no cure exists. However, the fear of transmission into the general

> populace is unwarranted, particularly when that fear is based on the belief that someone with HIV merely living in the same area poses a risk to the health and safety of the community. Irrational hysteria and public panic cannot support activity that violates the FHA and is clearly discriminatory.[93]

In another significant case, a Pennsylvania state court held that a local zoning ordinance violated the FHAA by prohibiting group homes in single family residential neighborhoods.[94] The ordinance excluded group homes for dependent children, individuals over 62, and persons with mental retardation or physical disabilities from locating in single family residential neighborhoods. The court held that the ordinance violated both the equal protection clause of the U.S. Constitution and the FHAA, concluding that a group home is "designed specifically to be a home like other homes."[95] Under the FHAA, unrelated individuals with disabilities who live together in a group home constitute a family.

The U.S. Dept. of Justice has filed a lawsuit under the FHAA against an Illinois city for refusing to grant a building permit for a group home for adults with mental retardation.[96]

(b) May a landlord or property owner refuse to rent or to sell to an individual believed to be HIV-positive? May a landlord ask a prospective tenant if he or she has AIDS?

No. The FHAA regulations specifically include HIV infection in the list of impairments in the definition of "handicap." Thus, the law prohibits the denial of housing to individuals who have, or who are suspected of having, HIV infection.

A landlord is allowed to refuse to rent to someone whose "tenancy would constitute a direct threat to the health or safety of other individuals," and therefore the landlord may ask the applicant questions about her "ability to meet the requirements of . . . tenancy."[97] However, a landlord may not ask the applicant if she or anyone with whom she associates has a disability.

FOOTNOTES - ANTIDISCRIMINATION STATUTES

1. The statutes discussed in this report generally refer to "handicap" or "handicapped persons," but this report will use the terms "disability" or "persons with disabilities," except when referring to specific statutory language. The term "disability" is used in this report to refer to individuals covered within the scope of a statute's definition of "handicaps."

2. 29 U.S.C. sec. 701 *et seq.* The Americans with Disabilities Act of 1989, which as of October 1989 has passed the U.S. Senate and is awaiting action in the House of Representatives, would greatly expand federal civil rights protections for persons with disabilities, including those with HIV infection. See section 5 of this chapter.

3. 29 U.S.C. sec. 791.

4. 29 U.S.C. sec. 793.

5. 29 U.S.C. sec. 794.

6. The Civil Rights Restoration Act of 1987, Pub. L. No. 100-259, sec. 4, 102 Stat. 28, 29-30 (1988), as codified in 29 U.S.C. secs. 794(b) and (c).

7. 29 U.S.C.A. sec. 706(8)(B).

8. *School Board of Nassau County, Florida v. Arline*, 480 U.S. 273, 282 (1987).

9. *See Chalk v. U.S. District Court of Central District of California*, 840 F.2d 701, 708-09 (1988); *Doe v. Centinela Hospital*, No. CV 87-2514 PAR (PX), slip op. at 4-6 (C.D. Cal. June 30, 1988); *Doe v. Dolton Elementary School Dist. #148*, 87 C 8713, slip op. at 5-6 (N.D. Ill. June 23, 1988); *District 27 Community School Board v. Board of Education*, 502 N.Y.S. 2d 325, 336 (N.Y.Sup. Ct. 1986).

10. *See* The Civil Rights Restoration Act of 1987, Pub. L. No. 100-259, 102 Stat. 28, 31 (1988), as codified in 29 U.S.C.A. sec. 706(8)(C); Legal Counsel Memorandum, U.S. Dept. of Justice, *Application of Section 504 of the Rehabilitation Act to HIV-Infected Individuals* (Sept. 27, 1988) [hereinafter referred to as DOJ Memo]; *Doe v. Centinela Hospital*, No. CV 87-2514 PAR (PX) (C.D. Cal. June 30, 1988).

11. *See* Institute of Medicine, *Confronting AIDS* 44 (1986); DOJ Memo, *supra* note 10, at 6-8 (quoting Surgeon General C. Everett Koop).

12. *Arline*, 480 U.S. at 284-86; *Centinela*, No. CV 87-2514 PAR (PX), slip op. at 4-6; *cf. Ray v. School Dist. of DeSoto County*, 666 F. Supp. 1524, 1533 (M.D. Fla. 1987); see text accompanying note 7.

13. *See Kohl by Kohl v. Woodhaven Learning Center*, 865 F.2d 930 (8th Cir. 1989).

14. *Arline*, 480 U.S. at 288.

15. *Chalk v. U.S. District Court of Central District of California*, 840 F.2d 701, 706-09 (1988); *Doe v. Centinela Hospital*, No. CV 87-2514 PAR (PX) (C.D. Cal. June 30, 1988); *Ray v. School District of DeSoto County*, 666 F. Supp. 1524, 1535 (M.D. Fla. 1987); *Thomas v. Atascadero Unified School Dist.*, 662 F. Supp. 376, 380 (C.D. Cal. 1987).

16. *Update: Universal Precautions for Prevention of Transmission of HIV, Hepatitis B Virus, and Other Bloodborne Pathogens in Health-Care Settings*, 37 Morb. & Mort. Weekly Rep. 377 (June 24, 1988); Friedland and Klein, *Transmission of the Human Immunodeficiency Virus*, 317 New Eng. J. Medicine 1125 (1987).

17. *See* Fischl, et al., *Evaluation of Heterosexual Partners, Children, and Household Contact of Adults with AIDS*, 257 J.A.M.A. 640 (1987); Friedland, et al., *Lack of Transmission of HTLV-III /LAV Infection to Household Contacts of Patients with AIDS*, 314 New Eng. J. Medicine 344 (1986).

18. *See Chalk v. U.S. District Court of Central District of California*, 840 F.2d 701, 706 (9th Cir. 1988); *Doe v. Dolton Elementary School Dist. #148*, 87 C 8713, slip op. at 8 (N.D. Ill. June 23, 1988); *Glover v. Eastern Nebraska Community Office of Retardation*, 686 F. Supp. 243, 251 (D. Neb. 1988), *aff'd*, 867 F.2d 461 (8th Cir. 1989); *Barton v. New York City Commission on Human Rights*, 531 N.Y.S.2d 979, 985 (N.Y. Sup. Ct. 1988).

19. *Recommendations for Prevention of HIV Transmission in Health-Care Settings*, 36 Morb. & Mort. Weekly Rep. 1 (Aug. 21, 1987); *Education and Foster Care of Children Infected with Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus*, 34 Morb. & Mort. Weekly Rep. 517 (Aug. 30, 1985). *See also* American Academy of Pediatrics, Committee on School Health, Committee on Infectious Diseases, *School Attendance of Children and Adolescents with Human T Lymphotropic Virus III/Lymphadenopathy-Associated Virus Infection*, 77 Pediatrics 430 (1986).

20. Education for All Handicapped Children Act of 1975, Pub. L. No. 94-142, 89 Stat. 774, 775 (codified at 20 U.S.C. secs. 1232, 1400, 1401, 1405-20, 1453).

21. 20 U.S.C.A. secs. 1412, 1415.

22. 20 U.S.C.A. sec. 1415(f); *see Martinez v. School Board of Hillsborough County, Florida*, 861 F.2d 1502, 1503 (11th Cir. 1988); *Doe v. Belleville Public School District #118*, 672 F. Supp. 342, 343-44 (S.D. Ill. 1987).

23. 20 U.S.C. sec. 1401(1).

24. *See Martinez v. School Board of Hillsborough County, Florida*, 861 F.2d 1502, 1506 (11th Cir. 1988).

25. *Robertson v. Granite City Community School District No. 9*, Civ. 88-3268, slip op. at 3 (S.D. Ill. May 4, 1988); *Doe v. Belleville Public School District #118*, 672 F. Supp. 342, 344-45 (S.D. Ill. 1987); American Bar Association, *AIDS: The Legal Issues* 197 (1988).

26. 100 Stat. 796, 797, 20 U.S.C.A. sec. 1415(f); *Martinez*, 861 F.2d at 1504.

27. *Robertson*, slip op. at 4-6; *Belleville*, 672 F. Supp. at 343-44.

28. *See Doe v. Dolton Elementary School Dist. #148*, 87 C 8713, slip op. at 9-10 (N.D. Ill. June 23, 1988); *Thomas v. Atascadero Unified School Dist.*, 662 F. Supp. 376, 381-82 (C.D. Cal. 1987); *Ray v. School Dist. of DeSoto County*, 666 F. Supp. 1524, 1536 (M.D. Fla. 1987).

29. *Martinez*, 861 F.2d at 1505-06.

30. Pub. L. No. 100-430, 102 Stat. 1619 (1988), 42 U.S.C. secs. 3604(f)(1)-(3), 3605(a)-(c).

31. H.R. Rep. No. 711, 100th Cong., 2d Sess. (1988)[hereinafter House Report].

32. 24 C.F.R. sec. 100.201; 54 Fed. Reg. 3245, 3288.

33. See text accompanying note 14.

34. 42 U.S.C. sec. 3604(f)(9).

35. 42 U.S.C. sec. 3604(f)(3)(B).

36. House Report, *supra* note 31, at 25.

37. 42 U.S.C. sec. 3604(f)(1)-(2).

38. House Report, *supra* note 31, at 24.

39. *See Baxter v. Belleville, Illinois*, No. 89-3354 (S.D. Ill. Aug. 25, 1989).

40. House Report, *supra* note 31, at 24.

41. House Report, *supra* note 31, at 23.

42. *U.S. v. City of Chicago Heights*, C.A. No. 89C4938 (filed June 20, 1989).

43. *See, e.g.*, Colo. Rev. Stat. secs. 24-34-401, 34-402; Fla. Stat. secs. 760.02, 760.10; Ohio Rev. Code Ann. secs. 4112.01, 4112.02.

44. *See* S. Brakel, J. Parry, B. Weiner, *The Mentally Disabled and The Law* 656 (1985).

45. Intergovernmental Health Policy Project, The AIDS Policy Center, *Executive Summary and Analysis: AIDS and Discrimination - A Review of State Laws That Affect HIV Infection, 1983 - 1988*, I-22 (1989) [hereinafter Executive Summary].

46. *Id.* at I-20. The three states are Georgia, Kentucky, and Tennessee.

47. Intergovernmental Health Policy Project, The AIDS Policy Center, State AIDS Reports, Aug.-Sept. 1988 at 7.

48. *Executive Summary*, *supra* note 45, at I-22.

49. *See id.*

50. *Raytheon v. California Fair Employment & Housing Commission*, 261 Cal. Rptr. 197 (Cal. Ct. App. 1989); *Barton v. New York City Commission on Human Rights*, 542 N.Y.S.2d 176 (N.Y. Sup. Ct. 1989); *Cronan v. New England Telephone Co.*, 41 F.E.P. Cases 1273, 1275 (Mass. Super. Ct. Aug. 15, 1986).

51. *See* Leonard, *Employment Discrimination Against Persons with AIDS*, 10 Univ. of Dayton L. Rev. 681, 690 & n.36 (1985).

52. *See, e.g.*, Cal. Gov't Code sec. 11135.

53. Intergovernmental Health Policy Project, The AIDS Policy Center, *AIDS: A Public Health Challenge* 5-6, 5-7 (1987); Flaccus, *Handicap Discrimination Legislation: With Such Inadequate Coverage at the Federal Level, Can State Legislation Be of Any Help?*, 40 Ark. L. Rev. 261, 268-69 (1986).

54. *Raytheon v. California Fair Employment & Housing Commission*, 261 Cal. Rptr. 197 (Cal. Ct. App. 1989); *Barton v. New York City Commission on Human Rights*, 542 N.Y.S.2d 176 (N.Y. Sup. Ct. 1989); *Cronan v. New England Telephone Co.*, 41 F.E.P. Cases 1273 (Mass. Super. Ct. Aug. 15, 1986).

55. *Hurwitz v. New York City Comm'n on Human Rights*, 535 N.Y.S.2d 1007 (N.Y. Sup. Ct. 1988); *Elstein v. New York Division of Human Rights*, No. 88-2130 (N.Y. Sup. Ct. Feb. 14, 1989); *G.S. v. Baksh*, No. 1987CP0113 (Ill. Human Rights Comm'n Sept. 26, 1988).

56. *See Executive Summary*, *supra* note 45, at I-27; Gostin, *Public Health Strategies for Confronting AIDS: Legislative and Regulatory Policy in the United States*, 261 J.A.M.A. 1621, 1628 (1989).

57. Intergovernmental Health Policy Project, The AIDS Policy Center, Intergovernmental AIDS Reports, May-June 1989 at 9.

58. *Id.*

59. *Id.*

60. *Id.*; Intergovernmental Health Policy Project, State AIDS Reports, Oct.-Nov. 1988 at 10.

61. Md. Health Occ. Code Ann. secs. 14-504 (physicians); 7-313 (nurses); 4.5-311 (dentists); 18-310 (social workers); 13-315 (physical therapists); 9-314 (occupational therapists); and 19-313 (speech-language pathologists).

62. Intergovernmental Health Policy Project, Intergovernmental AIDS Reports, May-June 1989 at 9.

63. *Raytheon v. California Fair Employment & Housing Commission*, 261 Cal. Rptr. 197 (Cal. Ct. App. 1989); *Cronan v. New England Telephone Co.*, 41 F.E.P. Cases 1273, 1274-75 (Mass. Super. Ct. Aug. 15, 1986); Flaccus, *supra* note 53, at 299.

64. Flaccus, *supra* note 53, at 303-05.

65. *But see* Flaccus, *supra* note 53, at 306-09.

66. S. 933, 101st Cong., 1st Sess., 135 Cong. Rec. S. 10701 (1989).

67. 42 U.S.C. secs. 2000d, 2000e.

68. *Doe v. Centinela Hospital*, No. CV 87-2514 PAR (PX), slip op. at 7-9 (C.D. Cal. June 30, 1988).

69. 865 F.2d 930 (8th Cir. 1989).

70. *See* Medical Overview, chapter II.

71. Association of Regional Center Agencies/AIDS Education Project, *AIDS in the Regional Center System: A Training Manual* 93 (Oct. 1989).

72. 34 Morb. & Mort. Weekly Rep. 517, *supra* note 19; *cf. Community High School Dist. 155 v. Denz*, 463 N.E.2d 998, 1003 (Ill. App. Ct. 1984).

73. *Kohl by Kohl v. Woodhaven Learning Center*, 865 F.2d 930, 935-37 (8th Cir. 1989); *Martinez v. School Board of Hillsborough County, Florida*, 861 F.2d 1502, 1505-06 (11th Cir. 1988).

74. *School Board of Nassau County, Florida v. Arline*, 480 U.S. 273, 288 n.18 (1987).

75. *Kohl*, 865 F.2d at 939.

76. *Kohl*, 865 F.2d at 944 (McMillan, J., concurring and dissenting in part).

77. *See Doe v. Belleville Public School Dist. No. 118*, 672 F. Supp. 342, 346 (S.D. Ill. 1987).

78. *See Martinez v. School Board of Hillsborough County, Florida*, 711 F. Supp. 1066, 1069-70 (M.D. Fla. 1989)(citing change in policies of the Centers for Disease Control and the American Academy of Pediatrics to reflect most recent information on modes of transmission). The CDC, which initially recommended precautions around all "body fluids," has amended this policy to limit precautions to blood, semen, and vaginal secretions. *Compare Recommendations for Preventing Transmission of Infection with Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus in the Workplace*, 34 Morb. & Mort. Weekly Rep. 681 (Nov. 15, 1985) with *Update: Universal Precautions for Prevention of Transmission of Human Immunodeficiency Virus, Hepatitis B Virus, and Other Bloodborne Pathogens in Health Care Settings*, 37 Morb. & Mort. Weekly Rep. 377 (June 24, 1988). However, the CDC has not yet changed its 1985 recommendations regarding the possibility of taking extra precautions when dealing with preschool-aged children, as well as some children with neurological disabilities, based on possible HIV transmission through body fluids such as saliva, urine, and feces. *See* 34 Morb. & Mort. Weekly Rep. 517, *supra* note 19. In contrast, the American Academy of Pediatrics (AAP) has updated its policies, eliminating the need to use extra precautions for children "who lack control of their body secretions," thus underscoring that most body fluids do not pose any risk of HIV transmission. *Compare* American Academy of Pediatrics, *School Attendance of Children With Human T Lymphotropic Virus III/Lymphadenopathy-Associated Virus Infection*, 77 Pediatrics 430, 431 (1986) *with* American Academy of Pediatrics, *Pediatric Guidelines for Infection Control of Human Immunodeficiency Virus in Hospitals, Medical Offices, Schools, and Other Settings*, 82 Pediatrics 801, 805 (1988). To date, no court has upheld the denial of services to children based on the older CDC guidelines; instead courts have relied on the more recent AAP recommendations to order children returned to the classroom. *See Martinez, supra.*

79. Fox, et al., *Saliva Inhibits HIV-1 Infectivity*, 116 J. Am. Dental A. 635 (1988); Friedland and Klein, *Transmission of the Human Immunodeficiency Virus*, 317 New Eng. J. Medicine 1125 (1987).

80. Massachusetts Reverses Policy on Exclusion From Day Care, 4 AIDS Policy & Law 9 (June 28, 1989).

81. *Thomas v. Atascadero Unified School Dist.*, 662 F. Supp. 376, 380 (C.D. Cal. 1987).

82. *Raytheon v. California Fair Employment & Housing Commission*, 261 Cal. Rptr. 197 (Cal. Ct. App. 1989).

83. National Association of State Boards of Education, *Someone at School Has AIDS: A Guide to Developing Policies for Students and School Staff Members Who Are Infected with HIV* 11 (1989).

84. *See Martinez v. School Board of Hillsborough County, Florida*, 711 F. Supp. 1066, 1071 (M.D. Fla. 1989).

85. *Id.* at 1071-72.

86. *New York State Ass'n for Retarded Children v. Carey*, 612 F.2d 644, 650 (2d Cir. 1979); *Community High School Dist. 155 v. Denz*, 463 N.E.2d 998, 1003 (Ill. App. Ct. 1984).

87. *Denz*, 463 N.E.2d at 1004.

88. *Martinez v. School Board of Hillsborough County, Florida*, 861 F.2d 1502, 1506-07 (11th Cir. 1988); *Carey*, 612 F.2d at 650; *Ray v. School Dist. of DeSoto County*, 666 F. Supp. 1524, 1534-35 (M.D. Fla. 1987); *Denz*, 463 N.E.2d at 1004.

89. House Report, *supra* note 31, at 24; Schonfeld, *"Five Hundred Year Flood Plains" and Other Unconstitutional Challenges to the Establishment of Community Residences for the Mentally Retarded*, 16 Fordham Urb. L. J. 1, 7-10 (1987-88).

90. 24 C.F.R. sec. 100.201 (a)(2), 54 Fed. Reg. 3288 (Jan. 23, 1989).

91. *See, e.g., Huntington Branch, NAACP v. Town of Huntington*, 844 F.2d 926, 935-36 (2d Cir.), *review declined in part and judgment aff'd*, 109 S. Ct. 276 (1988); *Metropolitan Housing Development Corp. v. Village of Arlington Heights*, 558 F.2d 1283 (7th Cir. 1977).

92. No. 89-3354 (S.D. Ill. Aug. 25, 1989).

93. *Id.*, slip op. at 36.

94. *In re Millcreek Township Zoning Ordinance*, No. 3313-A-1988 (Pa. Ct. of Common Pleas, Erie County July 25, 1989).

95. *Id.*, slip op. at 7.

96. *Baxter v. City of Belleville, Illinois*, No. 89-3354 (S.D. Ill. Aug. 25, 1989).

97. 24 C.F.R. sec. 100.202(c), 54 Fed. Reg. 3288 (Jan. 23, 1989).

IV. HIV TESTING, MEDICAL TREATMENT, AND INFORMED CONSENT

A. General Legal Findings

* In absence of a statute requiring mandatory testing, informed consent is necessary before an HIV test can be administered.

* States are enacting HIV-specific statutes that require specific informed consent before an HIV test may be administered.

* An adult is presumed to be competent to give informed consent; if judicially determined to be incompetent for purposes of making medical decisions, a substitute decisionmaker must be appointed to make testing decisions.

* A child under the age of majority generally is presumed to be incompetent to give informed consent; the parent or legal guardian is presumed to be the substitute decisionmaker. Many state statutes do provide exceptions allowing adolescents or "mature" minors to consent to certain medical procedures, including an HIV test.

* A physician or HIV testing center cannot refuse to administer an HIV test to a person with a developmental disability who is legally competent to give informed consent for this procedure.

* Testing, in order to deny services or benefits to the person being tested, violates section 504 of the Rehabilitation Act, as well as many state antidiscrimination statutes. Efforts to test persons because they have developmental disabilities may violate the equal protection clause of the U.S. Constitution.

* A federal or state governmental agency cannot order someone to undergo involuntary HIV testing unless the agency can show that testing serves an important governmental objective that cannot be achieved through less intrusive measures.

* Informed consent is required for treatment of HIV-related conditions. What type of consent is required for participation in experimental treatments is unsettled.

B. Analysis of Laws Governing HIV Testing

The law has long recognized that a physician who touches someone without consent is committing the tort of battery.[1] The law requires the physician to obtain "informed consent"

which contains three elements; the consent must be competent, voluntary, and knowing. *Competency* refers to the patient's mental or cognitive ability to make a decision about the medical procedure at issue. To be *voluntary*, consent must be freely given without coercion. *Knowing* consent refers to whether the patient receives sufficient information to make a decision. Each of these elements, which will be discussed in more detail below, are necessary to fulfill the physician's legal obligation to obtain consent before proceeding with any treatments or procedures. "Informed consent" encompasses all three parts of the legal definition.

1. Competency: State Statutes and Common Law

The law protects the right of individuals to make their own health care decisions. However, in order to give informed consent to any medical procedure, including the HIV antibody tests, the law requires, among other things, that a person be competent to make reasoned decisions. As used here, competency is a legal status. It is not a single determination or status; rather an individual's competency can change depending upon the type of decision to be made. While an individual with a mental disability may be legally incompetent to enter a contract, he may have legal competence to make certain medical decisions. The fact that an individual has a developmental disability does not, by itself, make him legally incompetent to consent to medical treatment. In fact, unless the disability affects cognitive or intellectual abilities, the disability is irrelevant to determining legal competency. For all individuals, legal competency to give informed consent to medical treatment depends on three factors: 1) the person's age, 2) the person's mental capacity, and 3) the legal decision at issue.

a. Adults

The law presumes that an adult is competent to give consent to treatment unless there has been a judicial order stating otherwise.[2] This presumption is not negated merely because an individual has a developmental disability. Rather, there must be a judicial determination that the person lacks the competence to make the type of decision in question. Even if an individual has been adjudicated incompetent, the court can restrict the scope of the incompetency order. Thus, if a court appoints a guardian to make decisions on behalf of a person with developmental disabilities who has been adjudicated incompetent, the guardian's decisionmaking authority may be limited. An individual may retain the right to make medical decisions, including the decision whether to have an HIV test, despite having been found incompetent to make other decisions.[3]

State laws vary as to the legal requirements necessary to find an adult incompetent. However, most statutes employ one of the following tests for determining incompetency: 1) whether a person is unable to properly care for herself, or 2) whether a person is unable to make rational decisions concerning her person.[4] In addition, statutes usually require a finding that the individual has a particular impairment, such as mental retardation or other developmental disability, or has any impairment that affects decisionmaking capacity.[5]

The fact that a person with a mental disability withholds permission to conduct an HIV test is not grounds for declaring the person incompetent. The law allows an adult to make her own choice, even if that choice is contrary to what most adults would do. The decision to have the HIV test involves numerous considerations, and reasonable persons may reach different

conclusions. Therefore, denial of consent, by itself, is not sufficient to indicate irrationality and support a finding of incompetency.

If an adult is legally competent to give informed consent, and requests that an HIV test be performed, then refusal to administer the HIV test based solely on the fact that the person has a developmental impairment would constitute discrimination. Once it is determined that an individual is legally competent, even if the individual has a mental disability she has the right to make her own medical decisions.

b. Children

The law generally regards children -- in most jurisdictions anyone under the age of 18 -- as incompetent to consent to decisions on medical treatment. Since a child is legally incompetent to make a decision, that power rests with a substitute decisionmaker. In most cases this will be the child's parent. However, for children in the custody of a public child welfare agency, that agency may have the authority to act as the substitute decisionmaker.

Although the law generally views children as legally incompetent to consent to medical treatment, older children may have legal authority to give consent. Many states have enacted mature minor or emancipated minor statutes, allowing teenagers to make decisions otherwise vested in their parents or legal guardians. These laws recognize that adolescents are no longer incapable of making reasoned decisions; as they approach adulthood they assume increasing responsibilities and decisionmaking authority. Some statutes give adolescents authority to consent to certain types of medical decisions, such as treatment for venereal disease.[6] As of January 1, 1989, seven states had enacted HIV-specific statutes that allow mature minors to give informed consent to HIV testing without also obtaining parental consent.[7] Other states have specifically addressed the question of whether adolescents may consent to testing without parental approval. For example, Wisconsin regulations specify that a minor may give written consent to HIV testing if he is "of reasonable maturity." Colorado's law allows minors above the age of 16 to seek treatment or services without parental consent.[8]

No cases have tested the application of the mature or emancipated minor statutes to adolescents with developmental disabilities. Under these statutes the law recognizes that some adolescents have the maturity to make certain types of decisions as if they were adults. Applying these statutes to adolescents with a developmental disability, an argument could be made that these adolescents should be presumed competent to make medical decisions unless adjudicated otherwise. However, if the adolescent has a mental or cognitive disability, then a strong argument could be made that the child would not be covered by these statutes, and a substitute decisionmaker would be required.

2. Substitute Decisionmaker

a. Guardian

If an adult is adjudicated incompetent to make medical decisions, and a guardian is appointed, the guardian has to make decisions on behalf of her ward. The law recognizes at least three possible approaches. First, the guardian could act in the best interest of the ward; this means the guardian's decision is based on what a reasonable, competent person would decide to

do under the circumstances. The second approach, followed in a majority of states, is the substituted judgment standard. Under this standard, the guardian must make the decision the ward would have made if he was competent.[9] The third approach, known as the unified consent standard, combines the best interest and substituted judgment standards. Where it is clear what the ward would want, the guardian should carry out that decision; otherwise a best interest view should be employed.

Even if a guardian has legal authority to make medical decisions, some decisions are deemed so intrusive (such as abortion, sterilization, or life-saving treatment) that court approval also is required. An argument could be made that, in a somewhat different way, an HIV test also is extremely intrusive, and therefore requires special court approval. The effects of the test on a person's life, including the implications for personal privacy and other rights, are so extensive that the decision requires the extra legal protection of judicial review before being authorized. However, it is more likely that most courts would find that HIV testing does not rise to the level of intrusiveness or danger inherent in the procedures noted above. The test itself is not a life-saving treatment, nor does it involve fundamental bodily issues such as childbearing. As long as the guardian receives sufficient information about the consequences of testing, and provides specific consent, then the guardian probably has authority to consent to testing.[10]

b. State Custody

The state bears responsibility for the health and safety of individuals in its custody, including those living in state institutions such as schools, residential facilities, and habilitation centers. If an adult with a developmental disability lives in an institution, the administrator or medical director of the facility might have statutory authority in a few states to consent to medical treatment.[11] However, statutes may limit the extent of this authority, requiring that consent come from the disabled individual if she is capable of understanding the proposed treatment.[12]

The fact that an individual lives in an institution does not, by itself, signify legal incompetence to consent to medical procedures, including an HIV test. However, an argument may be made to require testing of individual residents based on specified medical indications or recognized high-risk behaviors. The reason for requiring testing in this situation is that an institution has a responsibility to provide each resident with appropriate medical treatment; HIV testing might be appropriate if the resident exhibits certain symptoms associated with HIV infection, or engages in high-risk behaviors that can result in HIV infection. However, even in these situations, the institution must obtain informed consent, either from the individual or the appropriate substitute decisionmaker, before administering the HIV test. The only exception is if the institution has statutory or regulatory authority to order HIV testing of residents.

States have adopted different approaches to the issue of HIV testing of residents. Colorado's Department of Health has implemented new policies which require state mental retardation facilities to test all clients and new admissions.[13] New Hampshire permits HIV testing of individuals committed to a state hospital, without obtaining informed consent, but only if the test is necessary for the placement and management of such individuals.[14] At present, these policies have not been challenged to determine whether the government has sufficient justification to order persons to submit to testing without consent. [See section 6] Several other states reject mandatory testing and instead recommend that institutions test residents only if there are clinical

symptoms suggesting exposure, a history of high-risk behaviors suggesting possible exposure, or continued uncontrollable behavior presenting significant risk of transmission. California permits institutions, or local health officers, to adopt their own policies on HIV testing.[15]

c. Children Under the Care of the Child Welfare System

For children in foster care, the question of who has authority to make decisions regarding medical care is more complicated. Children enter foster care through one of two mechanisms — voluntary or involuntary placement. So called voluntary placement occurs when a parent chooses to place her child with a child welfare agency, usually by executing a formal agreement. Involuntary placement requires a court order removing the child from the parent's custody and placing the child in the custody of the child welfare agency.

For voluntary placements, state statutes and the placement agreements govern questions about who has decisionmaking authority. Generally, the public agency will have legal authority to make routine medical decisions on behalf of the child, while the parent retains the right to consent to major, non-emergency surgery.

For involuntary placements, juvenile court laws usually define custody, clarifying the rights and responsibilities of the parents and the child welfare agency. Under these statutes, the agency's custody rights usually include the obligation to provide medical care. Assuming there has been no termination of parental rights, statutes may divide medical decisionmaking authority, giving the agency the right to make regular medical decisions, while leaving consent authority with the parents for extraordinary medical care.[16]

A public welfare agency retains legal custody of a child when it places the child with a private agency or foster parent. This means that the agency will continue to have the legal authority to make medical decisions on behalf of the child. An agency may delegate certain decisionmaking responsibilities to a foster parent; these delegations are governed by state statute, agency regulations and policies, and the contract between the agency and the foster parent. Generally, foster parents may be authorized to make routine medical decisions for the child as part of their day-to-day care responsibilities, but the agency retains the right to make major medical decisions.

3. Elements of Informed Consent: Voluntary and Knowing

As mentioned earlier, "informed consent" contains three elements: it must be competent, voluntary, and knowing. Competency was discussed earlier, for adults and children. To be voluntary, consent must be freely given based on adequate information to make a reasoned choice. Evidence of coercion, duress, undue influence, or deceit casts doubt, and possibly invalidates, a person's consent. Given the social and psychological implications of a positive HIV test, it is reasonable to expect that the individual or substitute decisionmaker will seek the physician's advice or assistance in considering whether to undergo testing. The physician must be careful not to increase the pressure, or try to coax the individual into making a particular decision.

Knowing consent refers to the patient's receipt of sufficient information to make a decision. The law offers two alternative standards to guide physicians in determining the quantity and

quality of information to provide. The first standard, used in a majority of states, requires a physician to follow customary disclosure practices in her community; in other words, the physician must provide the level of information that other local physicians would provide under the same or similar circumstances.[17] A minority of states employ a different standard, requiring the physician to provide the information that a reasonable patient requires to make an informed decision.[18]

Almost half the states have enacted statutes requiring that HIV testing be voluntary and based on the individual's informed consent.[19] Some of these statutes specify what information a physician must provide to a patient in order to obtain informed consent. Generally, these statutes require explaining the medical, personal, and social implications of taking the test. For example, Maine's statute defining informed consent to HIV testing requires that a patient have an actual understanding about the nature of the test, to whom the test results may be disclosed, how the test results will be used, and the reasonably foreseeable risks and benefits resulting from the test.[20]

Although to date no court has reviewed the issue of what information about an HIV test must be given to a patient, a court might view the increasing number of statutory enactments on informed consent for HIV testing as providing the necessary standard of disclosure. The guidelines and recommendations of major national medical and legal organizations, which encourage detailed disclosure about the medical and personal consequences of the HIV test, would support such a standard.

4. HIV Test: Specific or General Informed Consent?

If an adult is competent to make his own medical decisions, then under the doctrine of informed consent, he must possess sufficient information with which to make a decision on his course of treatment.[21] If the patient is a child, or an incompetent adult, then a substitute decisionmaker must give informed consent for medical treatment.

Informed consent is always required for any medical procedure, including a blood test. However, the form of consent may vary depending on the procedure involved. For medical procedures presenting risks of physical or mental consequences, such as surgery, drug treatment, or radiation exposure, specific consent to the particular procedure is required.[22] Procedures or treatments presenting little or no risk of physical or mental consequences do not require detailed explanation or specific consent; instead a physician could proceed if the patient's conduct implied consent, such as signing a general release or submitting to a test without objection.

A blood test is usually fairly routine, raising little objection since such tests do not present any inherent risks and are not considered intrusive in terms of the person's privacy.[23] Therefore, consent to an ordinary blood test may be implied from the patient's conduct rather than obtaining specific consent. Since the HIV test is a blood test it might be argued that, following usual medical practice, specific consent is not necessary. However, there are two problems with this point of view. First, although HIV testing may be a routine procedure, having such a test has extraordinary implications. Secondly, even if the HIV test is considered routine, it involves greater privacy intrusion than most other types of blood testing.

As of June 1, 1989, 23 states had enacted statutes requiring that physicians obtain specific consent before conducting an HIV antibody test.[24] These legislative mandates are in line with

the recommendations of leading legal, public health and medical authorities, including the American Bar Association, Centers for Disease Control, American Medical Association, and American Hospital Association.[25] For a person who is incompetent to give consent, then a duly authorized substitute decisionmaker must give specific consent.

Legislatures and medical authorities justify the need for obtaining specific consent because of the profound implications for personal privacy and risk to other fundamental rights of the patient, both from simply having the test as well as potential results. While the test itself may be simple, the physical and psychological consequences are not. HIV antibody testing constitutes a major intrusion into an individual's life; thus, seeking specific consent is fully consistent with the objectives of the informed consent doctrine -- preserving the patient's right of self-determination.

5. Discriminatory Motives for Testing

Requiring individuals to submit to HIV testing for purposes of segregation or exclusion will violate section 504 of the Rehabilitation Act, as well as many state disability antidiscrimination statutes. Some state statutes specifically prohibit HIV testing as a precondition for employment.[26] Other states prohibit testing as a precondition for receipt of services; for example, Maine and Vermont prohibit health care providers from requiring an HIV antibody test as a precondition for receiving care.[27] Regardless of whether the testing involves one person or is a blanket policy affecting all clients, new admissions or employees, testing may not be used as a means of denying services or employment to HIV-positive persons.

The use of testing for a discriminatory purpose is most evident when a program has found the individual meets all criteria for admission, yet denies services upon learning of a contagious disease. For example, a hospital drug rehabilitation program required all new patients to take an HIV test, and discharged anyone testing positive.[28] The fact that the program already admitted the patient signified that he had met all other criteria; the positive HIV test was the sole reason for his discharge. A federal district court invoked section 504, finding that the hospital treated the patient as disabled. In a settlement, the hospital agreed to drop its mandatory testing policy.[29]

Similarly, a mental retardation living and habilitation facility determined that an applicant was appropriate for admission except for the fact that he had hepatitis B.[30] Although in this case the facility did not require the applicant to be tested, the critical fact is that the admission decision depended solely on the applicant's having a contagious disease. It is not discriminatory, per se, to require an individual to be tested or to consider the fact that someone has a contagious disease. However, in order to comply with section 504 and other antidiscrimination statutes, a program would need to follow the "otherwise qualified" analysis to determine if the disease posed a significant risk to others, or created any other legitimate problems making that person unqualified for the services or position. A remote or theoretical risk of transmission is insufficient medical justification for testing individuals, and subjecting those who test positive to different treatment.[31] Engaging in this type of analysis might prevent decisionmaking based on irrational fears, and thus help avoid potential discriminatory actions under section 504.

Selective testing also raises potential constitutional problems under the equal protection clause of the fourteenth amendment. This clause "is essentially a direction that all persons similarly situated should be treated alike."[32] The fourteenth amendment applies only to state

governmental actions, not to actions by private individuals. If a government program singles out one group of individuals for different treatment, it raises concerns about discriminatory motives. Any government-ordered testing must serve a legitimate purpose in order to avoid violation of the equal protection clause.[33]

One court has upheld the constitutionality of a hospital request that a nurse reveal his HIV test results.[34] The court held that the hospital did not single out the nurse for different treatment; rather, the hospital was following its longstanding infection control policy which requires all employees exposed to infectious diseases to undergo testing if appropriate. This policy was not selectively applied; the court noted that another nurse, who suffered a needlestick from a patient diagnosed with AIDS, was similarly required to undergo testing. Furthermore, the policy required individual evaluation of each employee with an infectious disease, including consultation with the employee's physician, to determine what, if any, changes in work assignment were required. The court concluded that these procedures were rationally related to the legitimate purpose of safeguarding the health of other employees and patients, and therefore did not violate the equal protection clause.

6. Mandatory Testing: Search and Seizure Under The Fourth Amendment

The fourth amendment to the U.S. Constitution protects the "right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures."[35] The fourth amendment only applies to federal and state governmental actions, not actions by private individuals. A search or seizure is unreasonable when it violates a person's legitimate (or reasonable) expectation of privacy. Individuals have a reasonable expectation of privacy in the personal information contained in their body fluids, including blood.[36] Under the fourth amendment, government-ordered blood tests, including an HIV test, are considered an invasive procedure since they violate a person's reasonable expectation of privacy. Therefore, if the government wants to order HIV testing without consent, it must satisfy the fourth amendment's test: 1) HIV testing must accomplish an important governmental objective, 2) the government's need to order HIV testing outweighs the individual's reasonable expectation of privacy, and 3) no less intrusive means are available to accomplish the government's objective.[37]

Under this test, a Nebraska mental retardation agency violated the privacy rights of its employees by requiring them to undergo mandatory HIV testing. In *Glover v. Eastern Nebraska Community Office of Retardation* (ENCOR), the agency argued that testing certain direct care employees was necessary in order to protect clients from contracting the virus.[38] The Eighth Circuit Court of Appeals rejected this argument because the medical evidence showed little or no risk of transmission. Clients did not need protection from HIV by the agency because they faced a negligible risk from agency employees. The court disagreed with ENCOR that certain behaviors exhibited by clients, such as biting and scratching, made them significantly more susceptible to acquiring HIV, thereby justifying subjecting employees to compulsory testing. Indeed, the court found that the risk of transmission was "miniscule, trivial, extremely low, extraordinarily low, theoretical, and approaches zero."[39] While the court acknowledged that ENCOR's goal of providing a safe living and training environment was an important governmental objective, it found that mandatory testing would not significantly advance that

purpose. Therefore, under the fourth amendment, ENCOR had no authority to order mandatory employee testing.[40]

In certain limited situations, mandatory HIV testing has been found to advance important governmental objectives and outweigh an individual's reasonable expectation of privacy. A federal district court refused to stop the U.S. State Department from requiring an HIV test as part of the medical fitness program of foreign service employees.[41] Unlike ENCOR, the State Department's purpose in testing was not to reduce the risk of transmission; rather its purpose was limited to determining fitness for overseas duty. The court noted that foreign service employees must be prepared to serve anywhere in the world. Yet, if an employee was HIV-positive, he might require medical services unavailable in many countries. Furthermore, employees were already required to submit to a blood test as part of the routine medical examination for foreign service personnel; thus the court did not find that an HIV test was an added intrusion.[42] Thus, HIV infection could hinder or diminish an employee's ability to carry out his duties. The court held that since medical fitness was a longstanding qualification for overseas duty, the added qualification of being HIV-negative was a reasonable extension of this requirement.

A health facility's infection control policy might require employees to inform their supervisors of their health status, including actual or suspected contagious diseases. It could be argued that, under such a policy, ordering the employee to undergo HIV testing would not violate any privacy interests since the employee voluntarily agreed to abide by this condition as part of his employment.[43] Before a program could require an employee to undergo involuntary testing, however, it would have to show sufficient reasons to justify the suspicion that a particular employee may have HIV infection.

Despite the fact that an individual has little or no reasonable expectation of privacy, the government will be permitted to order testing only if it furthers an important governmental objective. The fact that an individual has little or no privacy interest does not give the government the automatic right to order testing. If testing does not advance an important governmental objective, then regardless of an individual's privacy interests, testing is constitutionally impermissible.[44]

A governmental agency may have an important objective in ordering testing, and testing may advance that objective, but if other means would also advance the government's objective, without requiring invasion of a person's privacy, then testing would be constitutionally impermissible. For example, if universal precautions, such as wearing gloves when working with blood, will protect employees, then testing as a means of protecting employees may be constitutionally impermissible.[45]

There is a significant difference between a testing policy applied to a large group of persons, and an infection control policy that suggests using testing on a case-by-case basis if there are reasonable indications that a person may be HIV-positive. The latter approach more closely defines and limits the need for testing, and better ensures individual evaluation. Mandatory testing policies applied to large groups, whether they be clients or employees, raise serious questions of discriminatory motive which clearly is not a legitimate basis to order testing. A policy that specifies the conditions for testing an individual, and establishes a reasonable nexus

between testing and the objective served by testing, stands a better chance of being judicially upheld.[46]

There have been relatively few instances of government-ordered testing. The one exception is mandatory testing of prison inmates. At least 12 state prison systems, as well as the Federal Bureau of Prisons, have established mandatory testing programs.[47] Many other state prison systems have rejected mandatory testing because it is not the most effective strategy for reducing transmission of HIV within correctional facilities and improving the quality of medical care for infected inmates. In addition, these prison systems contend that potential benefits are far outweighed by the disadvantages -- difficulty in preserving confidentiality of test results, potential violence against those identified as HIV positive, the costs and inherent logistical problems, and feasible alternatives to testing. These same rationales would be applicable to government-ordered testing in other types of institutions, such as developmental disability facilities. (It should be remembered that the fourth amendment applies only to government-run facilities, not private agencies.)

It is unclear whether mandatory HIV testing in prisons satisfies the fourth amendment test. Even if such testing survives fourth amendment scrutiny, the constitutionality of mandatory testing in other institutional settings is questionable. Prisoners have fewer constitutional rights as a result of conviction and incarceration. Prison officials are given greater leeway to implement policies to preserve prison security. It is highly unlikely that a developmental disability facility would be given the same latitude to implement a mandatory testing program for clients. Therefore, developmental facilities should be wary of applying principles used in HIV testing/prison cases to their own programs.

7. Consent to Medical Treatment

Although most of this chapter has examined informed consent in the context of decisions to undergo HIV testing, most of the analysis is applicable to decisions involving the course of treatment once an individual is diagnosed with HIV infection. So long as the individual is legally competent to provide consent, then the individual has the right to make his own choices about treatments. In the case of children, generally a substitute decisionmaker will have authority to give consent. However, adolescents in states with mature or emancipated minor statutes may have the right to give consent to treatment without the necessity of obtaining consent from a substitute decisionmaker.

As of October 1989, only AZT had been licensed by the U.S. Food and Drug Administration to treat HIV directly. Other drugs are approved to treat HIV-related symptoms, such as thrush or pneumonia. Most drugs that are being developed to directly treat HIV remain in the experimental stage. This raises numerous questions about access to experimental treatments and who may consent to such treatments. On the one hand, persons with developmental disabilities should not be denied the opportunity to participate in clinical trials that may provide them with the only chance of gaining access to experimental drugs that could prolong their health. On the other hand, the fact that these treatments are at an experimental stage raises complex issues about weighing risks and benefits associated with such treatments. The issue is even more complex for children in the custody of a child welfare agency; it is unclear who has authority to give permission for the child to be enrolled in an experimental treatment program.

Individuals with developmental disabilities, or their substitute decisionmaker, should be informed about all possible treatments, including those in clinical trials. Decisions about participation should be made by the individual or the legally-authorized substitute decisionmaker. Participation in clinical trials should be an option available to persons with developmental disabilities to the same extent that such an option exists for anyone else with HIV infection.

C. Application of Laws to Testing

(a) Must a physician obtain informed consent from a person with a developmental disability before conducting an HIV test?

Informed consent is always required before conducting an HIV test, regardless of the individual's age or whether she has a developmental impairment. Certain developmental disabilities involving cognitive impairments can diminish the individual's legal capacity to give consent. Depending on the individual's mental competence, or age, informed consent for HIV testing may be obtained from a substitute decisionmaker, generally the individual's parent or court-appointed guardian.

Many states have enacted legislation requiring physicians to obtain specific informed consent, meaning that the physician must obtain express consent to the HIV test, often written, from the patient before proceeding. In addition, many statutes specify certain information that must be provided to a patient as part of the process of obtaining consent; this information generally includes an explanation of the HIV test, the significance of a positive result, and possible emotional and social implications. These statutes apply to everyone, including persons with developmental impairments, infants and children, or their substitute decisionmaker.

(b) Must a physician ensure that a person with a mental disability understands the nature and significance of the HIV test in order to comply with informed consent requirements?

Although both common and state statutory law requires that the patient be given adequate information about an HIV test in order to make an informed decision, curiously the law generally does not require that the physician ascertain that the patient understands the information provided. A physician's legal responsibility is to provide the type and amount of information that is customary to provide to patients facing a similar decision. Persons with mental disabilities might require a different quality and quantity of information in order to understand the implications of an HIV test, yet generally the law does not appear to require that physicians adapt their explanations to suit a patient's mental capacity. Some states have enacted HIV statutes specifying the content of such information, but no statute requires the physician to tailor the information to the mental capacities of each patient. This does not mean that a physician can ignore a person's mental disability and provide information that will not be understood by the patient. Since consent also must be voluntary, providing clearly unintelligible information to a person with a cognitive impairment could qualify as coercion. Whatever the

legal requirements, good medicine requires a physician to provide information that a reasonable person with a mental disability could understand.

(c) When can a guardian consent to an HIV test for an adult with a developmental disability?

As a general rule, guardians can give substitute consent to an HIV test if their guardianship includes authority to consent to similar types of medical procedures. This authority can be explicit or implied. Where such authority is missing, it is presumed that the individual has the right to consent to the test. This presumption is strengthened by the legal trend to treat the HIV test differently from other types of blood tests and require specific informed consent from a patient. Under specific informed consent, courts could narrowly interpret the guardian's authority to exclude consenting to an HIV test. Then, either the individual would be found competent to decide, or the court's incompetency order would require judicial approval for an HIV test.

Even if a guardian has authority to make medical decisions, the authority may be limited to certain types of decisions that do not include HIV testing. For example, a guardian might have authority only to make decisions concerning life-threatening conditions. Although HIV infection causes a variety of life-threatening diseases and conditions, failure to test for HIV antibodies does not present an immediate life-threatening situation. Nor can an HIV test be considered life-saving treatment; it is merely a diagnostic device. Therefore, a guardian with authority to consent to life-saving treatment does not necessarily have authority to consent to an HIV test.

The fact that an HIV test is involved does not mean that guardians may enlarge their otherwise limited decisionmaking power. For example, in *Guardianship of Anthony*, the Massachusetts Supreme Judicial Court overruled a probate judge's order that a man with mental retardation and his lover be tested by the state institution where they resided.[48] The probate judge had no legal authority to order HIV testing; the judge's guardianship of Anthony extended solely to decisions concerning the administration of antipsychotic medication.

(d) If a guardian has the legal authority to consent to an HIV test, what factors should guide the decision?

The law recognizes three alternative standards for guardianship decisions. In the majority of states, a guardian must make the decision based on what the ward herself would decide if she was competent to do so. The fact that the guardian would choose to do the opposite does not matter; the guardian is supposed to represent the wishes of the ward, not her own. In a second group of states, a guardian must make the decision based on the best interest of the ward: the guardian determines what a reasonable person would decide to do under the circumstances. In the final group of states the two standards are combined into a unified standard. First, a guardian must carry out the wishes of the ward, if known; if the ward's wishes cannot be determined the guardian would then make a decision based on the ward's best interest.

Most adults with developmental disabilities can express their feelings about whether to have an HIV test, and thus should have the opportunity to do so. Even under some best interest tests

and the unified standard, a guardian must attempt to ascertain the ward's preferences, and to carry them out if reasonable. The fact that the ward does not want to be tested is not necessarily an unreasonable decision; persons may have legitimate reasons for declining to be tested. The new state HIV testing laws requiring specific consent demonstrate that legislatures, pursuant to the recommendations of public health officials, are leaving the testing decision to the individual. An adult with a developmental disability, either himself or through a substitute decisionmaker, has the right to this same freedom of choice.

(e) Can the state consent to an HIV test for an adult with mental retardation whose unprotected sexual activity puts him at high risk of acquiring HIV?

The state's right to consent to testing depends on its legal authority, not on the sexual or other behaviors of the adult. The state may consent to testing only if it has the legal authority to consent to medical procedures similar to HIV testing. If the state's medical consent authority is limited to extradordinary or life-saving measures, then consenting to an HIV test would be outside the scope of its power. In *Guardianship of Anthony*, the Massachusetts Supreme Judicial Court upheld this principle when it struck down a probate judge's order that a mentally retarded man and his lover be tested merely on the basis that they engaged in homosexual activities.[49] If a state agency believes that HIV testing is necessary, yet lacks the authority to compel testing absent the client's informed consent, it may seek a court order as it would for other types of medical procedures requiring court review.

State employees, including physicians, must be careful to avoid any undue pressure which could invalidate an individual's informed consent. Persons under the care or custody of the state may be particularly vulnerable to pressure because they are often dependent on staff for information about HIV and AIDS, as well as seeking advice on medical decisions.

(f) Can an institution or program decide to add HIV testing to its routine medical examinations for all clients or applicants?

Having an HIV test as part of a routine medical examination required of all applicants is not, per se, illegal, provided that informed, specific consent is obtained before conducting the test. However, such a policy raises important questions about what the institution or program will do if the applicant refuses to give consent, or if the applicant's test results are positive.

Programs and institutions cannot automatically deny services or placement to an applicant because he refuses to take an HIV test, or because he tests positive. In either situation, the individual is considered disabled under section 504; a program will need to show that he is not otherwise qualified for admission. Federal regulations which prohibit employers from requiring pre-employment medical examinations or making pre-employment inquiries of applicants regarding disabilities would apply to HIV testing.[50] [For a complete discussion of issues of discrimination, see Chapter III, Antidiscrimination Statutes.] If testing is required, it must be in order to better serve the HIV-positive individual rather than to deny the individual services. A program considering routine testing must evaluate the reasons for wanting to test applicants, determining why HIV-related information is critical to providing services to the individual. If the

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information has no relevance to providing services, then requiring HIV testing cannot be legally justified.

Furthermore, mandatory testing by state agencies may constitute an unreasonable search and seizure in violation of the fourth amendment to the U.S. Constitution. Testing must serve an important governmental objective in order to justify the intrusion into the individual's right to privacy. Furthermore, the government must show that no less intrusive measures exist that would accomplish the same purpose. In most circumstances, stopping the spread of the virus, or protecting others from infection, is insufficient justification for testing because the risk of transmission in a particular setting is low and HIV testing does not offer any protection against transmission.

For example, in *Glover v. Eastern Nebraska Community Office of Retardation*, the court reviewed evidence of all possible modes of transmission from staff to client, or client to staff, including casual contact, biting and scratching in which blood is drawn, and attending to personal hygiene needs.[51] For each of these situations, the court found that the risk of transmission was either non-existent or extraordinarily low; therefore, mandatory staff testing could not be justified on the basis of preventing HIV transmission.

In contrast, obtaining an employee's HIV test results was upheld under the fourth amendment when it was applied to one individual, rather than all employees, based on reasonable medical evidence that the individual, a nurse, had been exposed to the virus.[52] The nurse performed invasive procedures where there was a significant risk of infection; while wearing gloves and other precautions could help to ameliorate the risk, evidence showed that the nurse did not always use such precautions. Mandatory testing of all employees or clients would be much harder to justify because blanket testing policies have little medical value in identifying infected persons and preventing the virus' spread, given the extremely limited modes of transmission.

(g) Can a program single out persons with developmental disabilities for testing, based on concerns that certain behaviors caused or exacerbated by the disability could create a significant risk of acquiring or transmitting HIV?

Efforts to single out individuals with developmental disabilities for testing could raise questions about discriminatory motives.[53] A risk of HIV transmission exists if anyone infected with the virus engages in certain behaviors, such as unprotected sexual activity or sharing intravenous drug needles. Singling out persons with developmental disabilities sweeps too broadly since there will not necessarily be any connection between the risky behaviors and the disability. A program that believes that certain individuals, whether they have disabilities or not, are at high-risk of acquiring HIV, must obtain informed consent before conducting the test. The one exception is if a state has enacted a statute permitting HIV testing without informed consent; however, these statutory exceptions are generally limited to very specific situations.

(h) Who, other than a parent, may consent to a minor being tested for the HIV antibody?

Legally, the minor's guardian may consent to the child's medical treatment. If it is a medical emergency, treatment may be given without the guardian's consent; however, this exception would not apply to an HIV test since it is a diagnostic test and thus unlikely to qualify as an emergency situation. Anyone who is the child's legal guardian may consent to the test. Usually, this is the parent. However, if the parent has voluntarily surrendered legal guardianship, or a court has transferred such guardianship to another (e.g., through a neglect, abuse, dependency, conservatorship or even custody proceeding), then this third party may consent to the child's test. For many infants and children with HIV infection, a public child welfare agency often has this third party decisionmaking status. Since any child born with the disease will have an infected mother, it is not unusual for such mothers to be too sick (or become too ill) or be ill-suited to care for the infant. As a result, many of these infants risk becoming "boarder babies;" these are babies who live in the hospital beyond the time it is medically necessary, while the public authorities attempt to find alternative living arrangements, preferably in a foster home. Most state child welfare agencies require HIV screening of high-risk children only when it is medically indicated; however, New Jersey routinely tests all high-risk foster care children.[54]

Older children generally contract HIV through sexual contact or sharing intravenous needles with an HIV-positive individual. These children are less likely to be in the abuse/neglect population, and more likely to come to the attention of public authorities through the runaway youth network. In every state there are runaway shelter programs serving this population. Since so many runaway children are sexually active, these centers expect that many of them may have, or will be at risk of contracting, HIV infection. However, unlike the public child welfare system, children utilizing these shelters are not wards of the state. Although many of these children are running away from abusive homes or have been "pushed out" by their parents, the parents retain the right to consent to their medical treatment. Thus, without parental consent, an HIV test cannot be administered unless the state has a mature or emancipated minor statute (see below). This admittedly raises a host of problems for the shelter. In some states, shelters are prohibited from contacting the youth's parents (an option permitted by the federal government in its funding law, Runaway and Homeless Youth Act). Othertimes, the minor may refuse to give his identity or tell where he is from, making parental notification impossible.

An exception to the general principle that only the legal guardian may consent to a minor's nonemergency medical treatment is the mature or emancipated minor rule. Under this rule, certain minors may consent to their own treatment. The parameters of this rule vary by state, both as to who is considered a mature or emancipated minor, and to what kinds of medical care such a minor may consent. Under this concept, older minors are often, by state law, given the authority to consent to treatment for venereal or sexually transmitted diseases. If HIV infection is classified as such a disease, then the mature minor may be able to consent to an HIV test, an option that the runaway shelter may wish to consider. Some state AIDS-specific laws also give mature minors this right.

(i) May a foster parent, preadoptive parent or other service provider of a child welfare agency consent to an HIV test for a child in its care?

In the absence of express authority by the child welfare agency that has obtained legal custody of the child, a foster parent, preadoptive parent or other service provider may not consent to the child being tested for HIV antibodies. These third persons, according to the placement or service contract, state law, and agency regulations, often have authority to consent to routine medical care for children in their direct care. Thus, for example, a foster parent may consent to a routine dental check-up for her foster child. These private actors, however, do not have authority to consent to nonemergency medical care of a more serious nature. Given the implications of a positive HIV test, this would not be considered routine medical care.

(j) May a child welfare agency consent to the child's participation in AIDS-related research?

Ethical and legal issues involving a child's participation in research is unsettled, and the complex details are beyond the scope of this report. However, the basic law is as follows. Federal regulations on research participation of minors often defer to state law, and many states are silent on this issue.[55] The basic rules are that parents must give *permission* (distinguished from consent) to this research, and children retain the power of *assent* (essentially a veto). The right to assent applies to children who are capable of assenting, taking into account such factors as age, maturity, and the psychological state of the child. The regulations also give minors the right to consent to participation if, under state law, they could consent to treatment. When third party permission is required, it lodges with the parent or legal guardian. The federal regulations, however, refer to an individual guardian, and do not seem to contemplate the situation in which a government agency may be a child's guardian. The regulations define situations where an Institutional Review Board (body within a research institute that is responsible for consent issues, among other things) may waive the consent requirement if it is "not a reasonable requirement to protect the subjects (for example, neglected or abused children)," provided certain safeguards are met. It is unclear whether these regulations would permit a child welfare agency to consent on behalf of a child to participation in HIV-related research. It is even more unclear whether a foster parent, private service provider or runaway shelter has such authority.

FOOTNOTES - HIV TESTING, MEDICAL TREATMENT, AND INFORMED CONSENT

1. F. Rozovsky, *Consent to Treatment: A Practical Guide* 4 (1984).

2. M. Macdonald, K. Meyer and B. Essig, *Health Care Law: A Practical Guide* 18-48 (1985).

3. *See, e.g.*, Guardianship for the Developmentally Disabled, Mich. Comp. Laws Ann. sec. 330.1602(1), Mich. Stat. Ann. sec. 14.800(602)(1).

4. S.J. Brakel, J. Parry and B. Weiner, *The Mentally Disabled and the Law* 372 (1985).

5. *Id.*

6. English, *Adolescents and AIDS: Legal and Ethical Questions Multiply*, 8 Youth Law News 1,3 (1987); Intergovernmental Health Policy Project, The AIDS Policy Center, *AIDS: A Public Health Challenge* 2-36 (1987).

7. *See, e.g.*, Mich. Comp. Laws sec. 14.15(5127); *see also* Gostin, *Public Health Strategies for Confronting AIDS: Legislative and Regulatory Policy in the United States*, 261 J.A.M.A. 1621, 1624 & n.59 (1989).

8. *AIDS: A Public Health Challenge*, *supra* note 6, at 2-37.

9. *The Mentally Disabled*, *supra* note 4, at 372.

10. The American Bar Association's Commissions on the Mentally Disabled and The Legal Problems of The Elderly convened a meeting of national experts in guardianship to develop recommendations for reform of the national guardianship system. Among the issues addressed were procedural due process for and legal representation of the proposed ward, determination of incapacity, and accountability of guardians. The recommendations are reprinted in 13 Mental & Physical Disability Law Reporter 271 (1989).

11. Ariz. Rev. Stat. Ann. sec. 36-512; R.I. Gen. Laws sec. 40.1-22-23.

12. R.I. Gen. Laws sec. 40.1-22-23; Cal. Welf. & Inst. Code sec. 7518.

13. *AIDS: A Public Health Challenge*, *supra* note 6, at 2-30.

14. N.H. Rev. Stat. Ann. sec. 141-F:5(IV).

15. *AIDS: A Public Health Challenge*, *supra* note 6, at 2-30.

16. R. Horowitz and H. Davidson, *Legal Rights of Children* 359 n.27 (1984).

17. 61 Am. Jur. 2d sec. 188.

18. 61 Am. Jur. 2d sec. 189.

19. Gostin, *supra* note 7, at 1624 & n.58; Intergovernmental Health Policy Project, the AIDS Policy Center, Intergovernmental AIDS Reports 1 (May-June 1989).

20. Me. Rev. Stat. sec. 23:19201(5-A); *AIDS: A Public Health Challenge*, *supra* note 6, at 2-35, 2-36.

21. *Salgo v. Leland Stanford Jr. University Board of Trustees*, 154 Cal. App. 2d 560, 317 P.2d 170 (Cal. Dist. Ct. App. 1957); *Natanson v. Kline*, 186 Kan. 393, 350 P.2d 1093 (Kan.), *clarified*, 187 Kan. 186, 354 P.2d 670 (Kan. 1960).

22. Spong, *AIDS and the Health Care Provider: Burgeoning Legal Issues*, 67 Mich. B. J. 610, 614 (July 1988).

23. Testimony of the American Hospital Association before the American Bar Association AIDS Coordinating Committee (March 2, 1988).

24. Gostin, *supra* note 7, at 1624 & n.58; Intergovernmental AIDS Reports, *supra* note 19.

25. American Bar Association, Comprehensive Policy on AIDS, Policy E2, promulgated by the AIDS Coordinating Committee, adopted by the House of Delegates on Aug. 9, 1989; Centers for Disease Control, *Public Health Service Guidelines for Counseling and Antibody Testing to Prevent HIV Infection and AIDS*, 36 Morb. & Mort. Weekly Rep. 509 (Aug. 14, 1987); Testimony of the American Hospital Association, *supra* note 23; Board of Trustees of the J.A.M.A., *Board of Trustees Report - Prevention and Control of Acquired Immunodeficiency Syndrome (An Interim Report)*, 258 J.A.M.A. 2097, 2101 (1987).

26. Intergovernmental Health Policy Project, the AIDS Policy Center, State AIDS Reports 11 (Oct.-Nov. 1988)[hereinafter State AIDS Reports].

27. *Id.*

28. *Doe v. Centinela Hospital*, No. CV 87-2514 PAR (PX), slip op. at 1 (C.D. Cal. June 30, 1988).

29. *Los Angeles Hospital Agrees to Drop Test Requirement for Rehab Program*, 4 AIDS Policy & Law, Jan. 25, 1989 at 1.

30. *Kohl by Kohl v. Woodhaven Learning Center*, 865 F.2d 930, 932 (8th Cir. 1989).

31. *New York State Ass'n for Retarded Children v. Carey*, 612 F.2d 644, 650 (2d Cir. 1979). *See also* Chapter III, Antidiscrimination Statutes.

32. *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432, 439 (1985).

33. *See id.* at 446.

34. *Leckelt v. Board of Commissioners of Hospital Dist. No. 1*, 714 F. Supp. 1377 (E.D. La. 1989).

35. U.S. Const. amend. IV.

36. *Schmerber v. California*, 384 U.S. 757, 767 (1966).

37. *Glover v. Eastern Nebraska Community Office of Retardation*, 686 F. Supp. 243, 250-51 (D. Neb. 1988), *aff'd*, 867 F.2d 461 (8th Cir. 1989).

38. 867 F.2d 461 (8th Cir. 1989).

39. *Id.* at 464 (quoting district court finding).

40. The Supreme Court refused to review the case, letting stand the Eighth Circuit decision. *Eastern Nebraska Community Office of Retardation v. Glover*, 58 U.S.L.W. 3287 (U.S. Oct. 30, 1989) (No. 88-1805).

41. *Local 1812, American Federation of Government Employees v. U.S. Dept. of State*, 622 F. Supp. 50 (D.D.C. 1987).

42. *Id.* at 53.

43. *Leckelt v. Board of Commissioners of Hospital Dist. No. 1*, 714 F. Supp. 1377 (E.D. La. 1989).

44. *Glover v. Eastern Nebraska Community Office of Retardation*, 867 F.2d 461, 464 (8th Cir. 1989).

45. *Leckelt*, 714 F. Supp. at 1377.

46. *Id.*

47. National Institute of Justice, *AIDS in Correctional Facilities: Issues and Options* 59 (1988).

48. 524 N.E.2d 1361 (Mass. 1988).

49. *Id.*

50. 45 C.F.R. sec. 84.14(A).

51. *Glover v. Eastern Nebraska Community Office of Retardation*, 867 F.2d 461, 463 (8th Cir. 1989).

52. *Leckelt v. Board of Commissioners of Hospital Dist. No. 1*, 714 F. Supp. 1377 (E.D. La. 1989).

53. *See New York State Ass'n for Retarded Children v. Carey*, 612 F.2d 644 (2d Cir. 1979).

54. U.S. General Accounting Office, *Pediatric AIDS: Health and Social Service Needs of Infants and Children* 5 (1989).

55. 45 C.F.R. sec. 46. 401-09.

V. CONFIDENTIALITY AND PROVIDER LIABILITY

A. General Legal Findings

* All individuals, including those with developmental disabilities, have a legal right to confidentiality of medical records, generally requiring the individual's consent for disclosure.

* Under general medical record or HIV-specific laws, physicians and other health care providers may share HIV-related information with other health care providers in order to secure appropriate medical treatment.

* HIV-related confidentiality statutes do not pose an absolute bar to disclosure. Most of these statutes specify certain categories of persons who may have access without obtaining the HIV-positive individual's consent; disclosure to all others requires that the individual give consent.

* Physicians have legal and ethical duties to preserve patient confidentiality; however, in certain extreme situations physicians may be *required* to disclose otherwise confidential information in order to protect the health and safety of third parties. Many state HIV confidentiality laws *permit* physicians to disclose HIV-related information under certain circumstances.

* Currently, it is unclear whether the law imposes on non-medical professionals, such as social workers or educators, a duty of protecting third parties similar to the duty imposed on physicians.

* Information about a person's HIV status should be disclosed only if less intrusive actions will not accomplish the same purpose, and only to the extent necessary to serve legitimate interests.

B. Analysis of Laws Governing Confidentiality and Provider Liability

1. The Individual's Right to Privacy: Limitations on Unauthorized Disclosure of Confidential Information

Privacy encompasses a person's right to be left alone; embodied within this concept is the notion that certain personal information belongs to the individual and, therefore, she has the right to decide whether or not to disclose such information to others. An individual's right to privacy is protected in constitutional, common and statutory law.[1] Physicians, social workers, and other service providers routinely receive personal information because their patients or clients choose

to reveal such information in order to obtain appropriate treatment or services. Service providers may also receive information about a patient/client from a third party. For example, a parent may provide information concerning her child, or a residential counselor may provide information concerning a client; all this information would be confidential. This information is disclosed for limited purposes, and the service provider is legally and ethically required to respect the confidential nature of this information by not disclosing it to others.

a. Confidential Information in Health Care Facilities

As a general rule, all information contained in medical records is confidential and must not be disclosed to anyone except the patient or the patient's authorized representative, such as a guardian or conservator.[2] This prohibition includes information concerning HIV infection. A number of exceptions apply to this general rule, and therefore would apply to HIV-related information. For example, a patient's consent need not be obtained before disclosing HIV-related information to hospital medical staff engaged in approved medical research or in a medical emergency.[3]

One of the major exceptions to non-disclosure of medical information is state laws requiring physicians or other health care workers to report to public health authorities the names of individuals with certain diseases.[4] Reporting requirements can be found in communicable or sexually transmitted diseases (STD) statutes, many of which encompass HIV/AIDS, or in HIV/AIDS-specific laws. This information enables public health officials to monitor the spread of contagious or infectious diseases, take appropriate measures to control their spread, and plan appropriate medical services.[5] All 50 states and the District of Columbia require health care providers to report new cases of AIDS to their state health departments.[6] These laws vary in terms of information collected. Some states require that identifying information, such as a person's name, be provided while other states do not require the individual's name, or require it only in certain limited situations. As of July 1989, 28 states required reporting of HIV-positive test results.[7] Most reporting statutes contain strict confidentiality protections; these safeguards are probably constitutionally required.[8]

There have been no challenges to mandatory reporting of AIDS cases to public health authorities. Most reporting statutes probably would survive constitutional scrutiny so long as: 1) the information is reasonably related to a valid public health purpose, 2) access to the information is limited to public health departments and their officials, and 3) the reporting scheme includes strict confidentiality protections.[9] Potential constitutional problems may exist in the few reporting statutes lacking confidentiality protections.[10]

Courts have restricted the permissible uses of information collected under public health reporting statutes. A New York trial court found that school officials violated the reporting statute by using public health surveillance data to identify children with AIDS for purposes of considering whether they could remain in school.[11] New York's reporting statute explicitly delineated how the health department could use the information it collected. The statute's confidentiality provisions created a "comprehensive and impervious shield" in order to foster an atmosphere of trust, enabling the health department to collect the information needed to carry out its responsibilities. The court acknowledged the importance of a case-by-case review of each child with AIDS, which depended on first identifying such children. However, the court warned

that using health department data, which was collected for a different purpose, could seriously undermine the department's continued ability to gather such information.

Most states already have statutes protecting the confidentiality of medical records from unauthorized disclosure to third parties, i.e., disclosure without the patient's consent. However, these laws do not necessarily apply to all types of patients, medical facilities, or medical records.[12] Furthermore, some statutes provide legal protection while others offer only non-enforceable assurances of confidentiality.[13] Some medical record statutes are specific to persons with mental retardation or other developmental disabilities.[14] In addition to medical record laws, confidentiality protections can be found in licensure laws (covering health care facilities and health care workers) and accreditation standards. Many health care providers also are under ethical constraints to maintain a patient's confidentiality.

Recognizing the special sensitivity of information concerning HIV-related information, and that existing medical record disclosure laws might not adequately protect such information, 44 states have enacted statutes specifically protecting the confidentiality of HIV test results or HIV-related information.[15] Under these laws, health care providers cannot disclose HIV-related information about a patient or client to a third party without obtaining consent. These statutes vary as to what information is protected, but generally they prohibit disclosure of an HIV test subject's identity, the test result, or any information that would identify the individual. However, all of these statutes permit unauthorized disclosure, either in specified circumstances (such as compliance with public health reporting laws) or to certain persons (such as a legal guardian or representative, the test subject's physician, and emergency care workers). Virginia's statute permits unauthorized disclosure to the parents of a minor.[16] Illinois requires the public health department to notify a school principal if a child is HIV-positive; the principal has discretion to disclose the identity of the child to the school nurse and the child's teachers.[17] Arizona's statute prohibits the public health director from informing a local school district that a pupil has tested positive for HIV unless it has an implemented a policy protecting the confidentiality of such information.[18] Maine authorizes disclosure of HIV test results to employees of the Department of Mental Health and Mental Retardation, to the extent such employees are responsible for the treatment or care of the test subject.[19]

Regardless of the confidentiality restrictions in medical record or HIV-specific statutes, all health care personnel actively involved in treating a patient, or who need information for internal administrative purposes associated with treatment, have access to a patient's medical records. No special consent from the patient is required to share this information. However, a few HIV confidentiality statutes, in attempting to protect a patient's privacy, may unintentionally restrict the physician's ability to provide appropriate treatment through the exchange of medical information. California initially adopted a strict HIV confidentiality law, prohibiting disclosure of test results to any third party without written authorization. In at least one instance, a physician concerned about possible criminal or civil penalties under this law refused to disclose an HIV diagnosis to health care personnel at a hospital to which the patient was being transferred.[20] Concerned that its HIV confidentiality statute could be similarly interpreted, the state of Washington amended the statute to clarify that disclosure prohibitions do not apply to customary methods of exchanging medical information used by health care providers to provide treatment and services to patients.[21]

The general rule for medical records -- that information can be shared with other health care workers involved in the person's treatment -- would apply to an HIV confidentiality statute. A court probably would not infer that a legislature intended to overrule this established principle without specific statutory language. More problematic may be determining under what circumstances, if any, a health care provider may share information with personnel in other service professions, including social service, education, or counseling staff. These people are not involved in the medical treatment of the individual; thus, the need to know a person's HIV status may not be as compelling. Yet, legitimate reasons exist to share this information. For example, a social worker may need to know a child's HIV status in order to secure appropriate foster care.

Under a confidentiality statute that lists exceptions to the general nondisclosure requirement, i.e., categories of persons who may receive HIV-related information without the patient's consent, any unauthorized release to persons not specified in the statute would be unlawful. The nondisclosure provisions apply to all individuals in possession of HIV-related information, including those who receive information under one of the exceptions. Yet, these laws are not absolute barriers to disclosure. If a physician obtains the patient's consent to release information to other parties, then these laws present no obstacles. Medical information is routinely disclosed by obtaining a patient's authorization, usually through his signature on a general release form.

Given the sensitive nature of information about HIV infection and the potential for discrimination if the information is improperly disclosed, the use of general release forms is inappropriate. Rather, health care providers should obtain specific, written consent for each proposed disclosure, unless unauthorized disclosure is specifically permitted by a relevant statute. For example, a patient's consent would not be required to disclose HIV-related information to a nurse providing medical treatment. But, the patient's specific, written consent is generally required before the same information can be disclosed to the patient's residential facility. Some states have already codified this requirement in HIV legislation;[22] if state statutes are silent, specific consent is still considered the wisest course of action. Patients can weigh the benefits of disclosure against possible repercussions, and make their own decision.

Moreover, there is precedent for stricter confidentiality protection regarding certain medical information. Federal law requires that patients in federally-funded substance abuse programs sign a special release before a physician may disclose any information from the patient's medical records to a third party.[23] The law specifies certain exceptions to this consent requirement, including medical emergencies and disclosure for treatment or research purposes. Some commentators have suggested that these laws might serve as a model for HIV infection, since HIV-related data often implicates highly personal information and unauthorized disclosure could engender negative consequences.

b. Confidential Information in Social Service Programs

Social service programs -- such as education, residential, child welfare, habilitation, and vocational -- have legal, and possibly ethical, obligations to preserve the confidentiality of information received in the course of providing services. The legal obligations arise from a variety of sources, including federal and state law, constitutional law, and common law. Confidentiality protections also can be found in licensure laws governing certain types of facilities or professions.[24] Once a third party has received HIV-related information, she is fully

bound by the relevant statutes to maintain its confidentiality. Unless further disclosure falls within a specified exception, the HIV-positive individual would have to give specific, written consent.

EDUCATION STATUTES: A student's education records can contain sensitive information concerning medical status; this is especially true for children receiving special education services. The Family Educational Rights and Privacy Act of 1974 (FERPA) protects the privacy of parents and students in educational agencies or institutions that receive federal education funds.[25] Programs receiving funds under the Education for All Handicapped Children Act (P.L. 94-142) or the Education of the Handicapped Act Amendments of 1986 (P.L. 99-457), as well as a host of other education programs, cannot disclose a student's "education records" or personally identifiable information without the written consent of the student (if she is 18 or older) or the student's parents.[26] Education records are defined as records maintained by an educational agency or institution that directly relate to a student.

The act contains several broad exceptions to its nondisclosure rule. First, in an emergency situation, consent is not required if "knowledge of such information is necessary to protect the health or safety of the student or other persons."[27] Second, school personnel, including teachers, may have access to the records for "legitimate educational interests."[28] Third, "education records" do not include "treatment" records of students 18 or older kept by health care professionals; thus treatment records of students between the ages of 18 and 21 receiving special education services may be disclosed without obtaining consent.[29] Finally, the act extends its consent requirements to anyone receiving confidential information; the fact that confidential information has been disclosed without consent does not mean that further unauthorized disclosure is permissible. To the contrary, the statute requires the written consent of the student or her parents before any subsequent disclosure occurs.[30]

The Education of the Handicapped Act also contains confidentiality safeguards, requiring that state plans include policies and procedures for protecting the confidentiality of "any personally identifiable data, information, and records collected or maintained" pursuant to the act.[31]

ADOPTION ASSISTANCE AND CHILD WELFARE ACT (AACWA): In the course of assisting qualified children and their families, child welfare agencies gain access to a great deal of personal information. Except in several specified circumstances, the AACWA requires that state plans for foster care and adoption assistance include safeguards restricting the use or disclosure of information concerning the child and her family.[32] Among the exceptions are disclosures related to: 1) the administration of the state plan or programs serving children and families under the AACWA; 2) the investigation, prosecution, or criminal or civil proceedings conducted in connection with a state plan or child welfare program; and 3) any audit conducted in connection with the administration of a state plan or child welfare program. The act permits states to adopt stricter disclosure standards.

In applying the AACWA exceptions to nondisclosure, public child welfare agencies must exercise professional discretion in determining whether to reveal information, and if so, under what circumstances and to whom. Disclosure to foster or prospective adoptive parents of health-related information concerning the child, as part of the administration of child welfare programs, is basic policy. Information about HIV status would be no different. Without

knowledge of a child's HIV status, the foster or adoptive parents cannot provide the child with appropriate medical attention and care, thus endangering the child's health.[33] Disclosing HIV-related information for the purpose of benefitting the child does not conflict with a fundamental purpose behind confidentiality laws -- protecting individuals from disclosures of personal information that can damage their interests. Finally, many states offer a higher subsidy to foster parents who care for children with HIV infection; these parents would need to know the child is HIV-positive in order to seek this higher subsidy.

The reasons favoring disclosure to foster parents certainly apply to prospective adoptive parents; the latter assume permanent legal responsibility for a child and therefore must know the child's medical history in order to provide appropriate care and protection of the child. In addition, these parents must negotiate an adoption subsidy with the state before the adoption is finalized. If prospective adoptive parents are not aware that the child they wish to adopt is HIV positive, they may fail to seek a subsidy, or negotiate a subsidy that may be inadequate to cover future medical, educational, or other needs.[34]

A public child welfare agency can be held liable for negligence if it, or a private agency under contract, fail to notify a foster family about a child's infectious disease, and as a result a family member suffers harm.[35] But, since HIV is transmitted through specific body fluids and cannot be passed through casual contact, it is highly unlikely that a foster parent could contract HIV by caring for an infected child. Only one incident of transmission from child to parent has been reported, and that involved heavy and unusual exposure to the child's blood without proper hand washing or use of gloves.[36] Given the minimal risk of HIV transmission from child to foster or adoptive parent, a public child welfare agency should make disclosure determinations based on the best interests of the child, and not on the basis of avoiding liability.

In terms of adoptive parents, a child welfare agency faces a strong possibility of liability for fraud if it knows a child's HIV status and yet misinforms or withholds this fact from the adoptive parents. In *Burr v. Board of County Commissioners of Stark County*, the Ohio Supreme Court found that the county welfare department intentionally misrepresented a child's medical history and family background. The adoptive parents relied on this misinformation in deciding to adopt the child; if they had known the child's true medical condition they would not have adopted him. The court held that the department was liable for medical and other expenses incurred in caring for the child, as well as damages for emotional distress.[37] California is the only state which permits annulment of an adoption based on a child's developmental disability or mental "deficiency" that existed, but was unknown by all parties, at the time of the adoption and which makes the child unadoptable.[38] In other states, courts may have authority to: 1) order the annulment of an adoption if an agency misrepresents or withholds information on a child's HIV status, or 2) award damages to compensate for the expenses incurred as a result of an agency's misrepresentation.[39]

2. Provider Liability: The Duty to Protect Third Parties From Harm

a. Common Law Duty

Although the law (common, statutory, regulatory) generally requires health care providers to protect the confidentiality of their patient's medical information, there are situations in which

they may have a competing obligation to protect a third party from harm, which permits or requires disclosure of otherwise confidential information. If a health care provider has a legal duty to protect a third party from harm, failure to do so could bring liability for negligence. Many questions remain unanswered concerning provider liability for injuries committed by patients, including whether the duty to protect others extends to potential transmission of HIV. This section examines the duty to protect and its possible application to transmission of HIV infection.

Physicians may be held liable for negligence if they permit others to be exposed to infectious diseases; in order to avoid liability, a physician has a duty to protect third parties by warning specific individuals at risk that the patient has a contagious disease.[40] A related legal duty, which has not been adopted in all states, requires psychotherapists to protect persons they know, or should know, are in serious danger of harm because of a patient.[41] The law imposes obligations in these two situations because physicians and therapists are in a unique position, due to their training, experience, and relationship with their patients, to foresee harm to third persons and to take steps to prevent the harm. This harm can be transmission of a contagious disease or violent acts. The physician or therapist does not need to have a personal relationship with the third party who could be hurt; as long as the physician or therapist knows that a specific individual is in danger of harm because of the patient, they may have a duty to protect that specific third party.[42]

Generally, the physician's or therapist's duty to protect others is limited to identifiable victims -- individuals known to be at risk of injury. There is no duty to protect the general public; a physician's or therapist's duty to protect others is triggered only when the patient poses a serious risk of danger to specific persons. Courts have been reluctant to extend a duty to protect the general public, reasoning that such a duty would impose an intolerable burden upon medical personnel or facilities. Instead, a physician must know of "specific risks to specific persons before a duty to warn exists."[43] Only one court has enlarged this duty beyond specific individuals, holding that a therapist owes a duty to protect a class of persons endangered by a patient's actions.[44] Physicians whose patients have a contagious disease may have a legal duty to warn family members and others known to be in close contact with the patient, such that they are at risk of infection.[45] In some cases, compliance with reporting statutes has been found to fulfill this duty, since public health officials then have the responsibility of notifying parties at risk.[46]

The contagious disease cases concerned diseases that have much greater risks of transmission than HIV, including typhoid fever, tuberculosis, and scarlet fever.[47] The extent of the duty to protect third parties was determined by the nature of the contagious disease and its mode of transmission. Since HIV is not transmissible through casual social contact, and the medical risk of transmission is low, a physician would not have a duty to warn persons merely because they were in close casual contact with a patient with HIV infection.

If a therapist or physician has a duty to protect a third party, that duty generally entails taking whatever steps are necessary to protect that person. Most of the psychotherapist cases have defined the therapist's obligation as a broad duty to take whatever steps are reasonably necessary to protect someone, rather than simply imposing a duty to warn.[48] In some cases, fulfilling the duty may mean actually warning the individual of his peril; thus it might be necessary to violate the confidentiality of the physician-patient relationship in order to adequately protect a third party. Courts generally require physicians to warn persons they know are at risk of contracting a

contagious disease, advising them of whatever precautions are necessary to avoid the risk.[49] Statutes can specify the actions necessary to fulfill a duty to protect others; Colorado's reporting law specifies that a physician fulfills his duty to warn a third party by reporting HIV test results to public health authorities.[50]

A patient's confidential information cannot be disclosed unless it is absolutely necessary to protect a third party's health and safety. In the psychotherapist cases, courts cautioned that physicians should not "routinely" reveal a patient's violent threats; disclosure was required only if "necessary" to protect someone and then, only if done "discreetly, and in a fashion that would preserve the privacy of [the] patient to the fullest extent compatible."[51] Similarly, the contagious disease cases found a duty to warn individuals at risk because that was the only effective means of preventing transmission to others. Applying these rationales to HIV, disclosure of a person's HIV infection would be necessary, thus permitting a physician to violate a patient's confidentiality, if it was the only means to protect others from contracting the virus. As concerns casual social contact, there would generally be no duty to take any actions. Programs that implement infection control procedures would have fulfilled their duty to protect employees, patients, or others from the possibility of transmission through blood spills.

Whether a similar legal duty to protect third parties could be imposed on other types of professionals -- educators, social workers, counselors -- remains unclear. The duty currently recognized by the law stems from special knowledge that the therapist or physician is presumed to have; in the case of contagious diseases, physicians are presumed to have the knowledge to diagnose a disease, and recognize if special precautions must be taken to prevent others from contracting it.[52] It is not clear that a teacher or social worker would be considered to have the same type of relationship, or extent of knowledge, as a physician. On the other hand, the Centers for Disease Control have recommended the use of infection control procedures in many settings, including the workplace, schools, day care programs, and health care facilities.[53] These procedures do not require extensive training and in most situations, according to health officials, are sufficient to eliminate any significant risk of transmission. To the extent that statutory or common law extends the duty to protect third parties to non-medical professionals, they may have a duty towards staff and clients to implement appropriate infection control procedures to protect their health.

The steps required to protect an individual at risk of HIV infection from sexual activities is more complicated. A legal duty to protect a third party can arise only if a physician (and perhaps other trained professionals) knows that someone is in serious danger of harm from a patient. Assuming that a duty exists, then it must be determined whether the endangered party can be protected without revealing the patient's identity. The infected individual should be counseled to disclose his condition to his partner, and be instructed in ways to practice safer sex.[54] In most cases, this should suffice. However, if the patient is unwilling or unable to disclose his condition, or the physician has good reason to believe that the patient is not practicing safer sex, then the physician may have a duty to warn the unsuspecting sexual partner.

Under all HIV-specific statutes, physicians have discretion whether to notify the spouse, sexual contact, or needle-sharing partner if they reasonably believe the partner is in danger of infection and the patient, after counselling, will not warn the partner. Since the authority to notify third parties is discretionary, physicians need not undertake affirmative steps to identify

such parties if a patient refuses to disclose their names.[55] Some of these statutes prohibit physicians from disclosing their patient's name or identity.[56] In order to underscore the fact that partner notification is discretionary, some of these statutes specifically prohibit civil or criminal liability against physicians, either for revealing confidential patient information or failing to do so.[57] All of these statutes, which apply to physicians or, in some cases, health care providers, probably override any common law duties to protect third parties. The discretion given to physicians does not necessarily extend to public health officials. Pursuant to STD, communicable disease, or HIV-specific statutes, public health officials may have a duty to notify persons at-risk of HIV transmission.[58]

b. State's Constitutional Duty to Protect Persons in Its Custody

The fourteenth amendment of the U.S. Constitution imposes a duty on the state to care and protect individuals within state custody. The state assumes responsibility for a person's safety and general well-being when it takes her into its custody, denying her the liberty to act on her own behalf.[59] Individuals with mental retardation, voluntarily or involuntarily committed to a state institution, have a constitutional right to live in reasonably safe conditions.[60] Lower courts have found a similar state duty to protect children in foster care from harm inflicted by their foster parents.[61]

The extent to which these constitutional protections apply to preventing HIV transmission is unclear. It might be argued that state facilities must provide residents with HIV education as a form of protection; knowledge about HIV transmission and safer sexual practices allows residents to protect themselves. Similarly, an argument could be made that disclosure of a resident's HIV infection is constitutionally required in order to protect another resident from a significant risk of transmission, thus permitting violation of confidentiality. However, there is substantial legal authority for the view that state officials would have to prove that breaching confidentiality was the least restrictive alternative, and that other actions would not adequately protect someone.[62] On the other hand, courts generally defer to state officials, allowing them to exercise their professional judgment regarding issues of care and custodial treatment. As long as qualified professionals exercise reasonable judgments, then they have fulfilled their constitutional duty. Therefore, state officials only would have to show that their actions reflected reasonable professional judgments about the risk of HIV infection and the measures necessary to prevent such transmission.

C. Application of Law of Confidentiality and Provider Liability

To date, 44 states have enacted HIV-specific confidentiality laws; in the next few months the remainder can be expected to consider confidentiality legislation. The answers given to the following questions would be true in most jurisdictions. However, due to variations in state laws, you should consult your state's HIV law, if one has been enacted, as well as other relevant laws to determine how they answer these questions.

(a) Can a *physician* disclose information concerning the HIV status of a person with a developmental disability to a third party?

As a general rule, a physician must obtain the patient's consent before disclosing information about HIV status to a third party; the fact that the patient happens to have a developmental disability or is a minor does not obviate the consent requirement. If the patient is incompetent to give consent, then the physician must consult with a duly authorized substitute decisionmaker. Unauthorized disclosure -- disclosure without the individual's consent -- of HIV-related information to the parents of an adult with a developmental disability would be unlawful, unless the parent was a guardian legally entitled to receive such information. Parents, as the legal guardians of children, can receive otherwise confidential medical information without the child's consent. The one exception might be for teenagers. If the state has a mature or emancipated minor statute giving the teenager the right to consent to an HIV test, generally the results of this test cannot be disclosed to the child's parent without specific consent. Disclosure would be permitted to a social worker or other specified employee of a child welfare agency having custody of an infant or child.

All states have laws protecting the confidentiality of medical records and prohibiting unauthorized disclosure. Most states, concerned that these laws may not be adequate, have enacted laws specifically prohibiting unauthorized disclosure of HIV test results, the fact that an individual has taken an HIV test, or HIV-related information. Some states have enacted provisions requiring specific consent to the release of HIV-related information; a general release form is not sufficient patient authorization. A few of these statutes require specific consent for each proposed disclosure.

The identity of the third party, and the reason for the disclosure, will determine whether disclosure without the individual's consent is permitted. HIV-specific state confidentiality laws enumerate persons or classes of people who may receive HIV information without the tested individual's consent. In all states with these statutes, HIV-related information can be disclosed to medical personnel participating in the treatment of an individual. Even in the absence of such a statute, these disclosures are permissible. Exchange of medical information, including HIV-related information, may be necessary to provide appropriate services and treatment; withholding such information could cause harm to the patient.

Unauthorized disclosure to non-medical service providers, such as staff at a residential facility or a social worker, may be more problematic. These individuals generally do not provide medical services, and thus an argument can be made that they have less reason to be told a person's HIV status. But, this medical knowledge may be important information in order to provide complete and suitable services. For example, a child welfare worker could require HIV-related information in order to arrange appropriate services and/or placement for a child. A number of state statutes authorize disclosure of HIV status to the state child welfare department for children in its care.

Physicians will want to consult their state laws to see if HIV-related statutes specify exceptions to the general rule of obtaining patient consent. Most states have not addressed the situation of disclosure to non-medical service providers, meaning that physicians and medical facilities must use care and discretion in determining those situations in which unauthorized disclosure is absolutely necessary to serve the client's interest.

(b) Can a *service provider* (non-medical professional, e. g. social worker or teacher) disclose a client's HIV status to a third party?

Generally, a service provider cannot disclose a client's HIV status to anyone else, without first obtaining the client's consent. Once a service provider has received information about a client's HIV status, she is legally bound to maintain the confidentiality of that information, unless the client authorizes disclosure to specific individuals. Many state HIV-specific confidentiality laws make it a crime to disclose this information without consent, authorizing a jail sentence, a fine, or both for unlawful disclosure.[63] These penalties apply to persons who legally receive the information and then inappropriately disclose it.

The fact that a client has a developmental disability is relevant only if, as a result, the client has been adjudicated incompetent and a guardian has authority to make decisions concerning disclosure of medical status. In this situation the service provider would have a legal obligation to tell the guardian about the client's condition. In fact, some HIV statutes specify that HIV-related information can be disclosed to guardians or legal representatives without obtaining the client's consent. If the client has not been adjudicated incompetent, he is presumed competent to decide whether to consent to disclosure. It is the individual's right to decide, not the service provider's, whether to tell his family about his medical condition. This does not preclude counseling the individual to divulge his condition to his family, but the service provider cannot make this decision on the individual's behalf.

If the client is a child in the custody of a child welfare agency, the agency may disclose HIV-related information to the parents since they retain some legal rights over the child. This would be true regardless of whether the state assumed custody of the child through a voluntary or involuntary placement. There is no legal duty to inform parents whose rights over the child have been legally terminated. If the client is a teenager, then the question of parental disclosure is more complicated. Under certain emancipated or mature minor statutes, and some HIV-specific legislation, teenagers may have the authority to consent to an HIV antibody test and the test results could be disclosed only to the minor. Virginia, however, specifically authorizes disclosure of HIV test results to the parents of minors; no consent is necessary.[64]

Service providers often share a client's medical information, which could violate some state HIV confidentiality statutes. In many states, however, exchange of HIV-related information may be at the discretion of the service provider. As a general rule, disclosure will be permissible only if it serves the client's interests. If the client's HIV infection does not affect the type of services to be received, then the information must remain confidential.

(c) How can a program director determine which employee(s) within her program require information about an individual's HIV status?

Most state laws do not answer the question of who within an institution can receive information about a person's HIV status. For example, a law may allow a public health official to notify a school that a student has HIV. But, the law probably would not specify who within the school should receive this information — the principal, the child's teachers, the school nurse? Should this information be released to all of these individuals, or only one of them? Programs should draft policies that specify which employees can receive HIV-related

what circumstances, and for what purposes. These policies should also stress that any employee receiving HIV-related information must maintain its confidentiality or face legal penalties.

Agency policies governing disclosure of HIV-related information generally state that such information should be released on a "need-to-know" basis. The purpose to be served by disclosure should govern the decision whether to reveal a person's HIV status, and if so, to whom. For example, a vocational program director may consider disclosing a client's HIV status to a counselor out of concern about possible accidents involving exposure to blood. Yet, in this situation, implementation of an infection control policy would be the most effective tool to prevent transmission of HIV, hepatitis B, or other blood-borne infections. In fact, programs ought to already have such policies in place; the need to create a safe, hygienic environment extends beyond the need to avoid HIV transmission. Disclosure of a client's HIV status solely for purposes of protecting against HIV transmission could cause staff to grow lax in implementing infection control procedures for all injuries involving blood. Therefore, the more effective prevention method is to assume that all clients have transmissible dieseases and use infection control procedures for everyone.

If the purpose of disclosure is to serve the client's medical needs, then disclosure is probably permissible. For example, a staff person at a residential facility or day treatment program who assists a client in taking medication, such as AZT, requires HIV-related information in order to adequately serve the client's needs. In such a case, though, disclosure should be limited to those persons assisting in the administration of medication. Disclosure to day care workers or group home facilities might also be necessary to monitor a child's condition. Loss of developmental milestones is a common result of HIV infection in children; knowledge that the child has HIV infection might be important in monitoring the child's development.

(d) Can a physician or service provider disclose the HIV status of a patient with a developmental disability in order to warn the patient's known sexual partner?

The fact that a patient or client also has a developmental disability would not, by itself, result in a duty to warn or protect others. Rather, any duty to protect third parties, by disclosing someone's HIV status or taking other appropriate measures, is triggered by the professional's ability to evaluate a significant risk of transmission and to intervene and prevent transmission from occurring. The law applies this duty regardless of whether a provider works for a state or private facility.

As with other persons with HIV infection, the HIV-positive client or patient should be educated on the risk of transmission and the need to disclose his condition to his sexual partners. This counseling should be in terms that the patient can understand. The patient should be given the opportunity to disclose his condition to those who could be at risk of transmission. If the patient refuses to disclose his condition, or is unwilling or unable to change his risky behavior, a physician might then be permitted to disclose the patient's condition to a sexual partner. No state requires physicians to warn a patient's spouse or sexual partner of possible risk of HIV transmission. Twelve states explicitly affirm that physicians do not have such a duty, but they do permit a warning at the physician's discretion.[65] Warning an individual about possible risk of HIV infection, and disclosing the identity of the source of the risk, are two different measures.

As a result of receiving a warning, an individual may figure out the source of the risk, but some state statutes prohibit physicians from directly revealing this information. State laws permitting warnings often provide physicians with immunity from civil or criminal liability for revealing confidential information.

Service providers might have a responsibility to protect the sexual partner if that person happens to be another client. Since a developmental disability can affect judgment and the ability to protect oneself, providers may have a special obligation to protect these clients. But, protection does not necessarily mean disclosure of another client's HIV status. Providing adequate supervision may be necessary for those clients with profound mental retardation who lack the capacity to understand HIV, venereal disease, and pregnancy. For clients with mild mental retardation, education is critical so that they can make informed choices about their sexual activities, and avoid infection. Providing condoms may be another means of protecting clients by helping them to protect themselves.

(e) Can a child welfare agency disclose information about a child's HIV status for purposes of *adoption*?

A state agency can disclose a child's HIV status for purposes of adoption; in fact, the agency could risk liability for fraud, and annulment of the adoption, if it knowingly withheld information about a child's HIV status. The more difficult question is when and how to disclose such information. The agency retains a responsibility to protect the child's privacy; unnecessary disclosure could hurt the child's interests. Agencies will want to check if their state has adopted an HIV confidentiality statute, to ensure that there are no possible conflicts with disclosure.

It is highly unlikely that there would be any barrier to disclosing a child's HIV condition to prospective adoptive parents; however, a possible conflict could arise over the timing of disclosure. For example, publication of a child's name and HIV status in a general adoption book could violate some state statutes since disclosure is not being made to a specific individual. On the other hand, some agencies as a matter of policy indicate to all prospective adoptive parents that a child has a serious medical condition but without revealing the exact disease or disability. Once a prospective adoptive parent expresses an interest in a particular child, then the agency provides more specific information, such as HIV status. These policies should not be in conflict with any HIV confidentiality statute.

(f) Can a child welfare agency disclose information about a child's HIV status for purposes of providing *foster care*?

A state agency can disclose a child's HIV status in order to obtain appropriate foster care services. Whether placing a child with a foster parent, or in a group setting, those providing daily care for the child cannot adequately fulfill their responsibilities to the child without knowing the child's full medical background. Medical information about a child is routinely disclosed to foster parents or other substitute caregivers, and HIV status would not be an exception.

Foster parents are, in effect, agents of the child welfare agency; they must follow the same rules and policies as the agency in caring for the child. This would include protecting the child's

privacy by not disclosing the child's HIV status. The agency retains custody over the child, and thus retains authority to decide the extent of disclosure permitted, pursuant to state law. An agency that decided to delegate authority over disclosure to the substitute caregiver would need to develop guidelines addressing under what circumstances the caregiver could disclose a child's HIV status. However, any authority given to the substitute caregiver cannot be broader than the authority of the agency. If state law limits the agency's ability to disclose HIV-related information, the caregiver would be similarly bound.

(g) Do service providers have a duty to protect their clients and employees from HIV transmission?

Service providers owe a duty to all clients and employees to protect them from foreseeable harm, including exposure to HIV. This duty would be similar to the duty to protect individuals from other blood-borne diseases, such as hepatitis B. Programs should already have policies and procedures delineating routine precautions; HIV does not require a different set of policies. If a program does not have such policies, they would be well-advised to adopt appropriate procedures covering all infectious and communicable diseases.

The duty to protect clients or employees does not mean that there is a duty to warn them that someone is HIV-positive. Rather, it means that providers must take whatever steps are necessary to ensure a safe environment. Service providers must remember that they have competing duties. While they must protect their clients and employees, they are also prohibited under many HIV confidentiality statutes from disclosing HIV-related information to these individuals. These statutes signify a strong public policy favoring nondisclosure, except in very limited circumstances. Providers should seek alternative ways of fulfilling their duty to protect, including use of infection control procedures, education, providing condoms and, if necessary, increased supervision or control of HIV-positive clients who cannot or will not control their high risk behavior. Disclosure of identifying information should be a last resort, taken only when other measures cannot protect persons from a significant risk of transmission.

While the legal duties delineated above apply to all service providers, state agencies have a constitutional obligation to provide reasonable care and safe environments to all persons within its custody. This includes individuals voluntarily or involuntarily committed to state care. The lower courts that have reviewed the matter have held that state custody covers children in foster care.[66]

No court has addressed whether the state's responsibility to provide safe conditions encompasses protection from the transmission of HIV. Courts have interpreted the right to safe conditions of confinement to encompass adequate food, clothing, shelter, medical and dental care, supervision, as well as protection from dangerous situations within the institution, such as slippery floors, crowding, harmful noise levels, and safety from attack by others.[67] If an individual within the state's custody contracted HIV because she was raped, or was the victim of a violent act resulting in exposure to blood, the state might already be held liable for the underlying violent acts.

A state institution has three choices in dealing with the risk of transmission through consensual sexual activity: 1) it can do nothing, 2) it can prevent residents from engaging in

sexual activity, or 3) it can help residents protect themselves from the risk of HIV infection. As a practical matter, the second alternative may be impossible to accomplish and may raise constitutional questions concerning state interference in personal rights. The third alternative, in certain limited situations, may necessitate warning a resident that a sexual partner has HIV infection. However, other measures may suffice that do not entail breaching confidentiality. For example, a state institution could help residents avoid the potential dangers or consequences of sexual activity by providing sex and HIV education.[68] Although the scope of training and education that must be provided to institutionalized persons is uncertain, minimally adequate training, as reasonably required to ensure safety, is constitutionally mandated.[69] It can be argued that service providers, who are aware that residents are sexually active but ignorant about HIV and its modes of transmission, are helping to perpetuate an environment that is constitutionally unsafe.

(h) If all measures, including warning a mentally disabled client that he is at risk of contracting HIV, prove inadequate, can an agency segregate the HIV-positive client in order to protect the uninfected client?

While agencies have a duty to protect all clients, they also have a legal obligation not to discriminate against a client on the basis of his disability. An agency cannot discriminate against an HIV-positive client, by segregating him or otherwise treating him differently solely on the basis of his HIV infection. The fact that a client has HIV infection does not create a significant risk of transmission through casual social contact. Thus, in the typical situation where the danger of transmission is minimal, any attempt to treat HIV-infected clients differently would violate section 504 of the Rehabilitation Act, as well as many state antidiscrimination statutes. (See Chapter III.)

If, however, as a result of impaired mental judgment, aggressive behaviors, or some other circumstance, an HIV-positive client presents a significant risk of transmission to other clients, then there might be sufficient basis for treating an HIV-positive client differently.[70] Whether or not a risk exists also will depend on the mental capacity of the other clients and other circumstances that would affect their ability to protect themselves. If other clients have impaired mental judgment or other conditions affecting their ability to protect themselves, the agency would have an obligation to protect those clients from harm. However, there may be ways to protect uninfected clients without resorting to segregation. For example, increased supervision might be sufficient to decrease the risk of transmission; such an accommodation might be required under section 504.

Various laws and statutes mandate that disabled persons, which would include those with HIV infection, be provided services in the least restrictive environment. This mandate does not necessarily conflict with any obligations to protect clients from contracting HIV infection. A physician owes each patient a duty to use reasonable skills, knowledge, and care in treatment. As with any decision concerning residential placement or other habilitation decisions, the service provider must "balance the various therapeutic considerations together with the possible dangers."[71] A service provider who recommends a less restrictive environment would not be liable if the client later transmits HIV to another as long as the provider carefully considered the individual's intellectual, emotional, and physical abilities and needs, the benefits and drawbacks

of a particular placement, and the nature and risk of HIV transmission.[72] If a provider concluded that a less restrictive placement was appropriate, she would have fulfilled her duty both to her patient and to any third parties.

A physician or therapist is not legally required to predict with absolute certainty whether a patient will act dangerously or transmit a communicable disease. Legal liability would not result because a provider's opinion to place an HIV-positive client in a less restricted environment ultimately proves wrong. Liability will result only if the professional's decision deviated from the customary standard of care.

(i) Do HIV confidentiality statutes preclude the use of multidisciplinary teams to resolve problems involving a specific HIV-positive client?

No. In certain instances, convening a multidisciplinary team can be an effective way of deciding how to handle competing interests that may be implicated when a client has HIV. Confidentiality may be maintained by not revealing the identity of the HIV-positive client; that information would generally not be relevant to determining appropriate procedures. It is more important to focus on the client's cognitive and behavioral capacities and designing appropriate programs that serve the client's needs while protecting others.

(j) What happens if a client mentions to other clients or staff that he is HIV-positive?

Generally, a person with HIV has the choice whether or not to disclose his condition. All clients who are diagnosed with HIV should be counselled that they may want to limit disclosure. Some clients may not understand the possibility of adverse consequences from openly discussing an HIV diagnosis, and therefore talk openly about their disease. Service providers cannot prevent clients from making such disclosures. Instead, the provider should educate all clients and employees about current medical precautions for avoiding HIV transmission. In addition, programs should have policies precluding discrimination on the basis of disability, including HIV infection. These measures can help avoid situations of panic if a client discloses, accidentally or intentionally, that he has HIV infection.

(k) Can service providers record a client's HIV diagnosis in its general client file?

HIV-related information should not be recorded in general files that are available to a large number of staff. Instead, HIV-related information belongs in a medical chart or other separate file system that can be secured, allowing access only to persons authorized to receive such information. Service providers must also be cautious in using euphemistic phrases. For example, a notation that "precautions around blood" should be observed can lead to unnecessary speculation about a patient's condition. Staff should be instructed to apply infection control procedures to all clients, thus avoiding the necessity of making special notations in a client's chart.

FOOTNOTES - CONFIDENTIALITY AND PROVIDER LIABILITY

1. Several state constitutions explicitly recognize an individual's right to privacy, including California, Florida, and Illinois. In addition, several state courts, including those in New York, Massachusetts and Pennsylvania, have interpreted their state constitutions to include a right of privacy. Lambda Legal Defense & Education Fund, Inc., *AIDS Legal Guide* 4-3 (1987).

2. O'Neill, *Confidentiality Concerns - The AIDS Patient, Part II*, 7 Topics in Health Records Management 74, 77 & n.14 (1987); *see, e.g.*, Cal. Health and Safety Code sec. 199.215. Medical records generally consist of four types of data -- personal, financial, social, and medical. They can be written, typed or in computer form, and can be found in one file or divided into several. A variety of state regulations specify the information required in medical records. *See* W. Roach, Jr., S. Chernoff, C. Esley, *Medical Records and The Law* 1-6 (1985). For purposes of this chapter and the laws discussed, medical records refers to any document that contains HIV-related information.

3. O'Neill, *supra* note 2, at 77 & nn.15-16.

4. The type of health care provider covered by confidentiality laws differs widely. Some laws cover only physicians, others extend their coverage to include additional health care staff, such as nurses or physical therapists, and another set of statutes simply refer to health care providers (or workers). This chapter will refer to physicians when a certain area of law tends to limit coverage, and to health care providers when an area of law generally applies to a greater number of health professionals. Readers are advised to review their relevant state laws to determine the professions covered.

5. Centers for Disease Control, 38 Morb. & Mort. Weekly Rep. 497 (1989); *see, e.g., Barsky v. Board of Regents of the University of New York*, 347 U.S. 442, 449 (1954); *Hawker v. New York*, 170 U.S. 189, 191-95 (1898); Comment, *Protecting Confidentiality in the Effort to Control AIDS*, 24 Harv. J. on Legis. 315, 330 (1986-87).

6. 38 Morb. & Mort. Weekly Rep., *supra* note 5, at 496.

7. *Id.*

8. *See Whalen v. Roe*, 429 U.S. 589 (1977); Gostin & Ziegler, *A Review of AIDS-Related Legislative and Regulatory Policy in the United States*, 15 Law, Medicine, & Health Care 5, 10 (1987); Intergovernmental Health Policy Project, The AIDS Policy Center, *AIDS: A Public Health Challenge*, 4-14 (1987).

9. *See Whalen v. Roe*, 429 U.S. at 600-02, 605-06; *United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 577-81 (3d Cir. 1980).

10. *See, e.g.*, N.H. Rev. Stat. Ann. sec. 141.1; Wash. Rev. Code Ann. secs. 70.05.090, 70.05.110; Comment, *supra* note 5, at 338.

11. *District 27 Community School Board v. Board of Education*, 502 N.Y.S.2d 325, 341 (Sup. Ct. Queens County 1986).

12. S. Brakel, J. Parry, & B. Weiner, *The Mentally Disabled and The Law* 575 (1985); *AIDS: A Public Health Challenge, supra* note 8, at 4-7.

13. *AIDS: A Public Health Challenge, supra* note 8, at 4-7.

14. *See, e.g.*, N.Y. Mental Hyg. Law sec. 33.01, 33.13-33.14, 33.16; Fla. Stat. sec. 393.13(3)(m); N.J. Rev. Stat. sec. 30:4-243; Colo. Rev. Stat. sec. 27-10.5-101, 27-10.5-120; *see Johnson v. Lincoln Christian College*, 501 N.E.2d 1380, 1384-86 (Ill. App. Ct. 1986).

15. *Bias Protections Lag Behind Confidentiality, Report Shows*, AIDS Policy & Law, Sept. 20, 1989, at 6; Gostin, *Public Health Strategies for Confronting AIDS: Legislative and Regulatory Policy in the United States*, 261 J.A.M.A. 1621, 1627, 1630 (1989).

16. Intergovernmental Health Policy Project, The AIDS Policy Center, State AIDS Reports, May-June 1989 at 8.

17. Ill. Rev. Stat. 1987 ch. 111 1/2, para. 22.12, sec. 2a.

18. Ariz. Sess. Laws 36-136(L).

19. Me. Rev. Stat. Ann. tit. 23, ch. 501, sec. 19203(7).

20. Binder, *AIDS Antibody Tests on Inpatient Psychiatric Units*, 144 Am. J. Psychiatry 176, 179-80 (1987).

21. State AIDS Reports, *supra* note 16, at 9.

22. Gostin, *supra* note 15, at 1624 & n.58.

23. 42 C.F.R. sec. 2.1, 2.31-2.35.

24. American Bar Association, *AIDS: The Legal Issues* 104 (1988).

25. 20 U.S.C. sec. 1232g ["Buckley Amendment"].

26. 20 U.S.C. sec. 1232g(b)(1), (d).

27. 20 U.S.C. sec. 1232g(b)(1)(I).

28. 20 U.S.C. sec. 1232g(b)(1)(A).

29. 20 U.S.C. sec. 1232g(a)(1)(C)(4)(B).

30. 20 U.S.C. sec. 1232g(b)(4)(B).

31. 20 U.S.C. sec. 1412(2)(D); 20 U.S.C. sec. 1417(c); 34 C.F.R. sec. 300.560-300.576.

32. 42 U.S.C. sec. 671(8).

33. *See, e.g.*, Centers for Disease Control, *Education and Foster Care of Children Infected with Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus*, 34 Morb. & Mort. Weekly Rep. 517 (1985); Child Welfare League of America Task Force on Children and HIV Infection, *Initial Guidelines* (March 1988).

34. 42 U.S.C. sec. 673; *see Burr v. Board of Comm'rs of Stark Co.*, 491 N.E.2d 1101, 1106-07 (Ohio 1986).

35. *See Vaughn v. North Carolina Dept. of Human Resources*, 252 S.E.2d 792 (N.C. 1979).

36. Centers for Disease Control, *Apparent Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus From Children to Mothers Providing Health Care*, 35 Morb. & Mort. Weekly Rep. 75 (1986).

37. *Burr*, 491 N.E.2d at 1106.

38. Cal. Civ. Code sec. 227(b).

39. *In re Lisa Diane G.*, 537 A.2d 131 (R.I. 1988); *Burr*, 491 N.E.2d at 1106.

40. 61 Am. Jur. 2d sec. 245; *Davis v. Rodman*, 227 S.W. 612, 614 (Ark. 1921); *Jones v. Stanko*, 160 N.E. 456 (Ohio 1928); *Skillings v. Allen*, 173 N.W. 663 (Minn. 1919).

41. *Tarasoff v. Regents of the University of California*, 551 P.2d 334 (Cal. 1976); *McIntosh v. Milano*, 403 A.2d 500 (N.J. 1979); *Lipari v. Sears*, 497 F. Supp. 185 (D.Neb. 1980); *see* Melton, *Ethical and Legal Issues in AIDS-Related Practice*, 43 Am. Psychologist 941, 941 (1988).

42. *Tarasoff*, 551 P.2d at 343.

43. *Gammill v. United States*, 727 F.2d 950, 954 (10th Cir. 1984); *Derrick v. Ontario Community Hospital*, 120 Cal. Rptr. 566, 571 (1975).

44. *Lipari*, 497 F. Supp. at 194.

45. *Skillings v. Allen*, 173 N.W. 663 (Minn. 1919); *Hofmann v. Blackmon*, 241 So.2d 752 (Fla. Dist. Ct. 1970); *Edwards v. Lamb*, 45 A. 480 (N.H. 1899).

46. *Gammill*, 727 F.2d at 950.

47. *Davis v. Rodman*, 227 S.W. 612, 612 (Ark. 1921); *Hofmann*, 241 So.2d at 752; *Skillings*, 173 N.W. at 663.

48. *Lipari*, 497 F. Supp. at 185; *McIntosh v. Milano*, 403 A.2d 500 (N.J. 1979); *Tarasoff v. Regents of the University of California*, 551 P.2d 334 (Cal. 1976).

49. *Skillings*, 173 N.W. at 663; *Edwards*, 45 A. at 480; *Hofmann*, 241 So.2d at 752.

50. Intergovernmental Health Policy Project, The AIDS Policy Center, *AIDS: Communicable and Sexually Transmitted Disease, Public Health Record and AIDS - Specific Laws* 36 (1988).

51. *Tarasoff*, 551 P.2d at 347.

52. *Davis v. Rodman*, 227 S.W. 612, 614 (Ark. 1921); *Hofmann*, 241 So.2d at 753.

53. Centers for Disease Control, *Update: Universal Precautions for Prevention of Transmission of HIV, Hepatitis B Virus, and Other Bloodborne Pathogens in Health-Care Settings*, 37 Morb. & Mort. Weekly Rep. 377 (1988); *Education and Foster Care of Children Infected with Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus*, 34 Morb. & Mort. Weekly Rep. 517 (1985).

54. *See Guardianship of Anthony*, 524 N.E.2d 1361 (Mass. 1988).

55. *See, e.g.*, N.Y. Pub. Health Law art. 44, sec. 2782(4)(c).

56. *See, e.g., id.*; W. Va. Code sec. 16-3C-3(d).

57. *See, e.g.*, Cal. Health & Safety Code sec. 199.25; W. Va. Code sec. 16-3C-3(d).

58. *See, e.g.*, Colo. Rev. Stat. sec. 25-21-1401-10; N.Y. Comp. Codes R. & Regs. tit. 10(A), sec. 2.6; *see also* Note, *Confidentiality, Warning, and AIDS: A Proposal to Protect Patients, Third Parties, and Physicians*, 4 Touro L. Rev. 301, 314 (1988).

59. *Youngberg v. Romeo*, 457 U.S. 307 (1982); *DeShaney v. Winnebago County Dept. of Social Services*, 109 S.Ct. 998 (1989).

60. *Youngberg*, 457 U.S. at 315-16; *Association for Retarded Citizens v. Olson*, 561 F. Supp. 473 (D.N.D. 1982), *aff'd*, 713 F.2d 1384 (8th Cir. 1983); *Lombard v. Eunice Kennedy Shriver Center for Mental Retardation*, 556 F. Supp. 677 (D. Mass. 1983).

61. *See Doe v. New York City Dept. of Social Services*, 649 F.2d 134, 141-42 (2d Cir. 1981), *after remand*, 709 F.2d 782, *cert. denied sub nom. Catholic Home Bureau v. Doe*, 464 U.S. 864 (1983); *Taylor ex rel. Walker v.*

Ledbetter, 818 F.2d 791, 794-97 (11th Cir. 1987)(en banc), *cert. denied sub nom. Ledbetter v. Taylor*, 109 S.Ct. 1337 (1989).

62. *See Shelton v. Tucker*, 364 U.S. 479, 488 (1960); *Thornburgh v. American College of Obstetricians and Gynecologists*, 476 U.S. 747, 765-67 (1986); *Cleveland Bd. of Education v. LaFleur*, 414 U.S. 632, 644-46 (1974); *see also* Schwartz and Costanzo, *Compelling Treatment in the Community: Distorted Doctrines and Violated Values*, 20 Loy. L.A.L. Rev. 1329, 1349-51 (1987).

63. *See, e.g.*, N.Y. Pub. Health Law art. 44, sec. 2783(1)(b), (2); Cal. Health & Safety Code sec. 199.21; Ill. Rev. Stat. 1987 ch. 111 1/2, para. 7313, 7315; Ill. Admin. Code tit. 77, sec. 697.170; Iowa Code sec. 141.24; Wis. Stat. Ann. secs. 103.15, 146.025(8).

64. *See* Va. Code Ann. sec. 32.1-36.1(10).

65. *See, e.g.*, N.Y. Pub. Health Law, art. 44, sec 2782(4); Md. Health-General Code Ann. sec. 18-336; *see also* Intergovernmental Health Policy Project, The AIDS Policy Center, *State Laws Governing Confidentiality of HIV-Related Information* (1989).

66. *See Doe v. New York City Dept. of Social Services*, 649 F.2d 134, 141-42 (2d Cir. 1981), *after remand*, 709 F.2d 782, *cert. denied sub. nom. Catholic Home Bureau v. Doe*, 464 U.S. 864 (1983); *Taylor ex rel. Walker v. Ledbetter*, 818 F.2d 791, 794-97 (11th Cir. 1987)(en banc), *cert. denied sub nom. Ledbetter v. Taylor*, 109 S.Ct. 1337 (1989).

67. *Association for Retarded Citizens v. Olson*, 561 F. Supp. 473, 486 (D.N.D. 1982), *aff'd*, 713 F.2d 1384 (8th Cir. 1983); *Society for Good Will to Retarded Children v. Cuomo*, 737 F.2d 1239 (2d Cir. 1984).

68. *See Guardianship of Anthony*, 524 N.E.2d 1361 (Mass. 1988).

69. *Youngberg v. Romeo*, 457 U.S. 307 (1982).

70. *See Doe v. Centinela Hospital*, No. CV 87-2514 PAR PX (C.D. Cal. June 30, 1988).

71. *Johnson v. United States*, 409 F. Supp. 1283, 1293 (M.D. Fla. 1976), *rev'd on other grounds*, 576 F. 2d 606 (5th Cir. 1978).

72. *Lipari v. Sears*, 497 F. Supp. 185, 193 (D.N.C. 1980).

VI. ISOLATION AND INVOLUNTARY CIVIL COMMITMENT

A. General Legal Findings

* Any state action to confine an individual with developmental disabilities and HIV, either by isolation or civil commitment, must be made on the basis of the individual's behavior; confinement solely on the basis of HIV status would be unconstitutional.

* ***Isolation*** of persons with developmental disabilities and HIV might be constitutional if based on the person's behavior, but only if the behavior poses an immediate significant risk of transmission of HIV. Unless there is a substantial and immediate danger of transmission, the person first should be given a realistic opportunity to control or change her behavior before any more restrictive action is taken.

* ***Involuntary civil commitment*** might be imposed if the person with developmental disabilities and HIV develops a serious mental impairment requiring treatment and if she exhibits behavior related to her disability which poses a danger to herself or to others.

* Any intrusive state action such as isolation or civil commitment must be accompanied by due process procedures.

* Less restrictive alternatives, such as compulsory education or training, are required before confinement may be used as a method of reducing the danger of HIV transmission.

B. Analysis of Laws Governing Restrictions on Individual Liberties

This chapter deals with state actions, specifically isolation and involuntary civil commitment, which are used to confine individuals to facilities or to their homes. Segregation within facilities is subject to antidiscrimination law, and is discussed in Chapter III of this report. Further, this chapter only addresses issues pertinent to older children and adolescents who have HIV infection and a disability, since states are highly unlikely to initiate isolation or civil commitment actions against infants.

1. Isolation

All states, under their police power, have the authority to combat dangerous communicable diseases by taking reasonable steps to restrict a person's freedom of movement or association.[1] Public health officials have long been granted reasonable discretion in imposing measures they

deem necessary to protect public health.[2] Two such measures are quarantine and isolation. Quarantine means confining all persons exposed to a contagious disease for the duration of the usual incubation period; isolation refers to the separation of infected persons from others during the period of communicability.[3] Although these terms refer to different public health measures, they are often used interchangeably. This chapter will use the term isolation to refer to both isolation and quarantine of an individual based on concern about transmission of HIV.

Isolation was once used widely as an effective way to stop the spread of communicable diseases. Today, its value as a public health measure has been greatly reduced by the development of more effective and less intrusive control techniques, such as antibiotics and sanitation.[4]

State authority to isolate citizens for public health purposes may be found in existing public health laws: communicable disease (CD) control law or regulations; or sexually transmitted disease (STD) control law or regulations.[5] All 50 states have isolation authority for communicable diseases; nearly half also have isolation authority for sexually transmitted diseases.[6]

Generally, CD and STD statutes can be divided into two categories. In the first category are statutes which allow public health officials to impose isolation only on diseases specifically listed either in the statute or in regulations as communicable diseases.[7] Most state CD and STD statutes predate knowledge of HIV and do not address HIV directly. As of February 1988, twelve states had added AIDS, by statute or regulation, to the list of communicable diseases; seven states had interpreted their STD regulations to cover AIDS.[8] In the second category are statutes which grant public health officials discretion to determine when a disease fits within the definition of a communicable disease, and permitting imposition of isolation as a means of controlling its spread. Traditionally, STD statutes are more likely to authorize use of isolation than CD statutes.[9]

A few states have enacted AIDS-specific legislation which permits public health officials to isolate "recalcitrant" persons who continue to engage in high-risk behaviors despite awareness of their danger to others. These statutes were a early legislative response to HIV; isolation authority has rarely been included in more recent AIDS-specific legislation. However, states continue to amend existing CD and STD statutes to authorize isolation and other procedures which may be applicable to persons with HIV.[10] In states with AIDS-specific legislation, an isolation order can be issued only after a finding that a person's actions pose a serious threat to public health, and less restrictive measures are unavailable to ameliorate the risky behavior.[11] Less restrictive measures may include compulsory education, counseling, testing, medical treatment, and cease and desist orders.[12]

In almost all those states which have statutes authorizing isolation of persons with AIDS through additions to CD or STD statutes or AIDS-specific laws, only persons with AIDS are covered, excluding persons with symptomatic or asymptomatic HIV infection.[13]

2. Constitutional Review of State Power to Order Isolation

a. Status versus Behavior

By infringing upon an individual's fundamental right to liberty, isolation implicates constitutional guarantees of equal protection and due process. Historically, the courts required only that a limited review of state authority be conducted to determine whether the state official had reasonable cause to isolate an individual. Courts deferred to the judgment of public health officials in determining whether an isolation order served a reasonable purpose. These cases even upheld isolation when less restrictive measures were available.[14]

Since the use of isolation to control the spread of HIV infection has been rare, no cases have arisen recently which challenge the constitutionality of the statutes or their application in this new context. While it has been suggested that a rational basis test may still apply to isolation actions,[15] a majority of legal analysts reviewing this question have concluded that strict scrutiny would apply.[16] Moreover, contemporary constitutional principles suggest that the use of isolation must be narrowly tailored to the situation, and imposed only after less restrictive alternatives have been found inadequate.[17]

Theoretically, isolation may be imposed either on the basis of status -- all persons with HIV infection or a defined subgroup such as persons within an institution -- or on the basis of dangerous behavior.[18] However, under modern constitutional principles, isolation of individuals solely on the basis of their HIV status would almost certainly be held unconstitutional.[19] A state lacks a compelling purpose to isolate individuals merely based on the fact they have HIV infection, because HIV cannot be transmitted through casual social contact. This type of status-based isolation would unnecessarily confine many persons whose behavior poses no significant risk of transmission to others. Also this isolation might amount to a life sentence since an infected individual will be infected for the remainder of his life.[20]

Given the position of public health authorities that status-based isolation would be both ineffective and counter-productive, states would have difficulty defending the use of such measures under either strict scrutiny or a rational basis review. Most public health officials have concluded that the use of punitive action will discourage people from being tested and seeking counseling and treatment, leading to a greater risk of continuing the spread of HIV.[21]

Further, to pass constitutional muster, it is likely that an isolation statute or order would need to be shown as the least restrictive alternative available. Many less restrictive alternatives are available to control HIV transmission; public health officials contend that education and counseling are effective approaches to controlling HIV transmission.[22] Public health authorities also conclude that measures aimed at changing individual behaviors better serve public health goals.[23] In fact, many states already have separate public health statutes authorizing the use of a wide variety of measures, including education, counseling, testing, medical examination or treatment, periodic inspections, or notification procedures.[24] In addition, given the large numbers of infected persons, and the need to isolate persons for the remainder of their lives, the cost and administrative burden of isolating every infected person would be prohibitive.[25]

Isolation on the basis of risky behavior would be constitutional if it is limited to those individuals whose behavior presents a serious threat to public health.[26] A state is more likely to

show a compelling purpose in confining an individual determined to be unwilling or unable to control his actions to prevent the spread of HIV. Under this standard, behavior-based isolation would be a measure of last resort, used only when less restrictive measures failed to change someone's behavior. In these situations — thought by public health authorities to be rare — isolation would be viewed as a reasonable means of preventing an individual from committing acts which pose a serious risk of imminent harm.[27]

Some public health officials argue that even behavior-based isolation is not a recommended strategy because it would not have a significant impact on controlling the spread of HIV on a large scale. It is difficult to locate and identify "recalcitrant" carriers, less restrictive public health orders may be more effective, and the threat of isolation would still discourage persons with HIV from seeking counseling and testing.[28]

Most AIDS-specific statutes which authorize isolation do so on the basis of recalcitrant behavior.[29] Similarly, contemporary CD and STD statutes permit behavior-based isolation only if a person's behavior poses a serious danger to public health that cannot be eliminated through less restrictive measures.[30] Older statutes grant broader authority, allowing the isolation of individuals based on their status.[31] However, any attempts to use such statutes on persons with AIDS are likely to be found unconstitutional.

Despite judicial deference to public health authority, historically courts did strike down isolation orders that were thinly veiled attempts to discriminate.[32] Statutes which apply only to persons with disabilities will be examined for hidden discriminatory purposes.[33] Any attempt to isolate particular groups would receive close judicial scrutiny. Mental disabilities do not, by themselves, increase the risk of HIV transmission. High risk behaviors increase that risk. With respect to persons who have developmental disabilities and HIV, state or local officials would have to show why public health objectives necessitate greater infringement on the liberties of them than of other persons infected with HIV.[34]

b. Procedural Safeguards

Historically, isolation statutes did not include procedural protections, and courts upheld isolation orders made without a due process hearing or other safeguards. Under contemporary due process principles, however, isolation would require similar procedural protections as required for involuntary commitment,[35] including: written notice, representation by counsel, a hearing with presentation of evidence, cross-examination of adversaries, and a clear and convincing standard of proof. As part of the hearing process, officials must show that no less restrictive alternatives are available, that isolation will be of limited duration, and that commitment is based on behavior, not status.[36] Also, any individual who is confined under an isolation statute has the right to apply to the court for a writ of habeas corpus to request her release.[37] Currently, most AIDS-specific statutes contain these procedural safeguards; in addition, some states have amended their CD or STD statutes to incorporate these procedural protections.[38]

All individuals in the custody of the state have a right to a safe environment and other protections.[39] Thus, public health officials have an obligation to avoid placing isolated citizens in unsafe environments.

3. Involuntary Civil Commitment

All states have the authority, under the *parens patriae* and the police power, to commit certain persons with mental disabilities to a hospital or other institution for treatment.[40] Unlike isolation statutes, however, involuntary commitment statutes are more circumscribed with the authority they grant to health officials.[41] Civil commitment statutes generally include the following criteria: 1) the person must have a mental disability; 2) as a result of the disability, the person is dangerous to self or others, or is unable to provide for her basic needs; 3) the person is in need of care or treatment; and 4) there are no less restrictive alternatives to institutional care.[42] Over three-fourths of the states have commitment laws pertaining solely to persons with mental retardation or developmental disabilities.[43] Civil commitment statutes do not directly address confinement of persons with HIV infection. They apply to persons with HIV infection only when the individual meets commitment criteria.

In contrast to many isolation statutes, civil commitment authority is accompanied by elaborate procedural protections. States vary in the degree of procedural protection afforded to persons with developmental disabilities, as opposed to those with a mental illness. Of those states with separate commitment laws for persons with developmental disabilities, nine grant full judicial proceedings to persons with developmental disabilities, but only if the patient requests it.[44] States may require less stringent due process procedures for individuals who are committed by their parent or guardian.[45]

Since involuntary commitment involves denial of personal liberty, commitment statutes and their application are also subject to substantive and procedural due process and equal protection limitations.[46] Civil commitment statutes tend to incorporate many of the constitutional protections, and now serve as a model for states considering updating their isolation statutes.[47] Under these statutes, commitment may be imposed on the basis of behavior, not on one's status of having a mental disability. A person must present a substantial risk of harm as a result of his mental disability, and this harm must be imminent. Furthermore, confinement on the basis of danger must be related to the individual's mental disability.[48] Since involuntary commitment is based on behavior, most statutes contain provisions for periodic review to monitor changes in behavior to determine whether confinement criteria continue to be met.[49] Many states limit long-term commitment orders to specific time periods, usually six months. At the end of this period, the individual must be released or a new commitment hearing held.[50]

Commitment procedures require authorized persons to petition the court while providing supporting medical evidence of the need for commitment. This is followed by a brief prehearing detention and medical exam on discretionary court order; written notice of the proceeding to the individual and an opportunity for the individual to be heard; representation by counsel; a full hearing following rules of evidence with the right to cross-examine adversaries; clear and convincing standard of proof; and the right to a hearing before a jury.[51]

Courts have not resolved the question of whether a civilly institutionalized person has a constitutional right to treatment or habilitation in the least restrictive setting. The Supreme Court has stated that civilly confined individuals have constitutional rights to something more than custodial care,[52] including the right to safety, freedom from bodily restraint, and to minimally adequate training in order to preserve other constitutional rights.[53] Some courts have gone

further, finding a right to training, habilitation, treatment, and services, both in the institution and in the community.[54] In addition, many state mental health statutes require treatment and other services.[55] Nevertheless, a number of courts have held that there is no constitutional right to treatment or habilitation in the least restrictive setting.[56]

C. Application of Laws Governing Isolation and Involuntary Civil Commitment

(a) On what basis may an individual with developmental disabilities and HIV infection be isolated?

Isolation constitutes a severe deprivation of liberty and therefore must be based on a compelling state interest. Under the public health authority all jurisdictions have the power to isolate and otherwise restrain contagious individuals. Isolation is rarely used to contain transmission of HIV. The status of being HIV-positive does not by itself create the type of risk that would justify state intervention. The public health power can be invoked only when a person's specific behaviors create a significant and imminent risk of transmission to other people. The health officer must have a reasonable belief based on medical evidence that a such a risk exists. Examples of behaviors that constitute a signficant imminent risk include frequent, unprotected sexual intercourse (particularly anal intercourse), or sharing intravenous needles.

Before the state may isolate an individual under its public health authority, the Constitution places on the state the burden of showing that there are no less intrusive means to achieve the same purpose, such as intensive education and counseling, or protecting those at risk.

Due to concerns about misapplication of isolation statutes to persons with HIV, the American Bar Association adopted the following policy:

> Isolation for public health purposes is a particularly serious infringement of liberty and is not generally appropriate for controlling the spread of HIV infection. However, if such isolation of an indivdual is sought, it should be ordered by a court only if it has found by clear and convincing evidence that:
>
> -- The individual is HIV-infected; poses a direct threat to public health as evidenced by a recent overt act endangering another person; and after notice, counselling and appropriate training will not restrict his/her own behavior to avoid a direct threat to public health; and
>
> -- The proposed isolation is necessary to protect public health and is the least restrictive alternative.[57]

(b) What procedural protections are due to an individual prior to isolation?

In most states, due process protections for isolation have not been as rigorous as the protections for civil commitment. Only some state statutes provide due process procedures prior to isolation of an individual infected with HIV. But because isolation is also a restriction of individual liberty, the same kind of due process procedures that are required prior to civil commitment may be applicable to isolation proceedings. At least one state supreme court, West Virginia, has extended its commitment proceedings to isolation actions.[58]

Responding to concern about unconstitutional restrictions on individual liberty through isolation, the American Bar Association adopted the following policy regarding due process for isolated individuals:

> In any proceeding in which the isolation of an individual is proposed or under review, stringent procedural protections should be afforded, including the rights to:
>
> -- Notice, representation by counsel, subpoena and present evidence, cross-examination, a verbatim transcript, and appeal;
>
> -- Judicial review after 30 days and thereafter no less frequently than every six months; and
>
> -- Appropriate treatment, habilitation and education directed toward changing the behavior that resulted in isolation.
>
> A court may grant an emergency non-renewable isolation order for a period of 72 hours or less upon application of a public health official who has filed with the appropriate court an affidavit establishing reasonable cause to believe that the facts and circumstances necessary for the imposition of isolation exist, and that there is an imminent, direct threat to public health.[59]

(c) On what basis may an individual with developmental disabilities and HIV infection be involuntarily civilly committed?

Civil commitment, like isolation, involves a deprivation of liberty that must be justified by a compelling state interest. The status of being developmentally disabled and having HIV is insufficient, by itself, to justify involuntary confinement, either under the Constitution or existing state laws.

Before the state may take a person into custody to control HIV transmission, there must be probable cause to believe that because of the person's behavior there is a significant and immediate risk of harm to self or others. Moreover, for that custody to continue, there must be a full due process hearing within a reasonable period of time in which a significant and immediate risk of harm is proven by clear and convincing evidence.

While the above standards are minimally necessary to meet constitutional substantive and procedural due process standards, the possible confinement of persons with developmental disabilities and HIV also depends on the statutes that are in effect in each jurisdiction. Most

existing civil commitment statutes were not intended for and probably do not cover persons with HIV, unless those persons have other characteristics which make them fall within an existing civil commitment scheme. A person with mental illness, such as AIDS dementia complex, or a developmental disability would be committed if there was proof that, as a result of the mental or developmental disability, the person was dangerous to self or others, or, in a few jurisdictions, unable to take care of herself. Before civil commitment statutes may be applied to anyone, many state statutes, and in all likelihood the Constitution, also require that there be no less restrictive alternatives to commitment available.

(d) Do risky behaviors related to HIV transmission constitute dangerousness under involuntary civil commitment statutes?

Under most existing involuntary civil commitment statutes, the dangerousness that is required must be directly related to the person's mental disability (mental illness or developmental disability). Where this is the case, behaviors that are risky because of the person's HIV status, and not related to his mental disability, will not be covered under the civil commitment statute. In the few jurisdictions in which dangerousness is not specifically tied to the person's mental disability, ordinarily non-dangerous behaviors that create a risk of HIV transmission, such as unprotected sexual activity, might subject a person to commitment without proof that the person's mental disability makes the person dangerous. However, even in those jurisdictions any of a number of substantive and procedural due process challenges to commitment laws might be forthcoming.

States need not rely on existing civil commitment statutes. They may enact new statutes to deal with HIV infection specifically. For example, Alabama, Maine, and Michigan have enacted laws authorizing commitment of persons with a CD or STD.[60] These statutes will be upheld as long as they serve a compelling state interest and otherwise meet minimal constitutional guarantees.

(e) Must states provide education about HIV infection to persons with developmental disabilities in state facilities?

Under the holding in *Youngberg v. Romeo*, states must provide sufficient habilitation to guarantee that conditions within a residential care or other custodial setting are not inherently unsafe so that other constitutional guarantees are violated.[61] What level of safety is constitutionally required is not altogether clear, particularly with respect to AIDS/HIV. When a person who is infected with HIV is confined to a state facility, the state's obligation to provide a safe environment to other residents may compel some special supervision or control of the resident with HIV infection to inhibit behavior which poses a significant imminent risk of transmission. Where two residents are engaging in a sexual relationship and one of the parties is HIV-positive, it would seem reasonable to presume that, at a minimum, education and counseling of the noninfected party would be required as a means of maintaining a safe environment.

Education might also be required for all residents where it is a less restrictive, viable alternative for the HIV-positive person. In addition, education can help provide a safe

environment for uninfected residents. Education should be presented in a manner that is appropriate to each individual's cognitive abilities.

(f) To what extent are states obligated to provide education, training, treatment, or other appropriate measures to change behavior which caused the individual to be isolated or commited to a state facility?

The Supreme Court decision in *Youngberg v. Romeo* establishes that once a state takes a person into a state institution, the state assumes an obligation to make sure that certain basic rights are protected. These rights include the right to a reasonably safe environment for everyone in the custodial setting, and the education and training necessary to exercise and enjoy those rights.[62]

Some state mental health statutes and state courts have enlarged these rights, stating that committed persons have a right to training, treatment, habilitation, and services. In these states, rights of committed persons might also be extended to isolated individuals. In the remaining states, committed or isolated individuals do not have an independent right to treatment in state facilities. However, the requirements to impose isolation only for a specific limited period of time, and to impose less restrictive public health measures when available, could be interpreted as an obligation to provide treatment or education to an isolated individual in order to relocate them to a less restrictive environment when possible.

Due to concern that once an individual with HIV infection is isolated, she could be permanently confined, the American Bar Association adopted the following policy to address th issue of treatment and habilitation:

> In any proceeding in which the isolation of an individual is proposed or under review, stringent procedural protections should be afforded, including the right to:
>
> --Appropriate treatment, habilitation and education directed toward changing the behavior that resulted in isolation.[63]

FOOTNOTES — ISOLATION AND INVOLUNTARY CIVIL COMMITMENT

1. American Bar Association AIDS Coordinating Committee, *AIDS:The Legal Issues* 53 (1988); Parmet, *AIDS and Quarantine: the Revival of an Archaic Doctrine*, 14 Hofstra L. Rev. 53, 57 (1985).

2. F. Grad, *Public Health Law Manual: A Handbook on the Legal Aspects of Public Health Administration and Enforcement* 46-7 (1973).

3. American Bar Association, *supra* note 1, at 53; Gostin, *The Politics of AIDS: Compulsory State Powers, Public Health, and Civil Liberties*, 49 Ohio St. L. J. 1017, 1027 (1989).

4. Gostin, *supra* note 3, at 1027; American Bar Association, *supra* note 1, at 53; F. Grad, *supra* note 2, at 46.

5. Gostin, *Public Health Strategies for Confronting AIDS: Legislative and Regulatory Policy in the United States*, 261 J.A.M.A. 1621, 1630 nn.108-09 (1989); Intergovernmental Health Policy Project, AIDS Policy Center, *AIDS: Communicable and Sexually Transmitted Diseases, Public Health Records, and AIDS Specific Laws* 12 (1988).

6. Intergovernmental Health Policy Project, *supra* note 5, at 47, 61.

7. W. Curran, L. Gostin, and M. Clark, *Acquired Immunodeficiency Syndrome: Legal and Regulatory Policy* i-ii (1986).

8. Intergovernmental Health Policy Project, *supra* note 5, at 12.

9. W. Curran, L. Gostin, and M. Clark, *supra* note 7, at i.

10. Intergovernmental Health Policy Project, AIDS Policy Center, legal data base (1989).

11. Gostin, *supra* note 5, at 1630 n.108.

12. Gostin, *supra* note 5, at 1627; Colo. Rev. Stat. sec. 25-4-1406 (1988).

13. Intergovernmental Health Policy Project, *supra* note 5, at 19.

14. Gostin, *supra* note 3, at 1033; Merritt, *The Constitutional Balance Between Health and Liberty*, 16 Hastings Center Rep., Supp. 2, 3 (1986); Parmet, *supra* note 1, at 75; American Bar Association, *supra* note 1, at 55.

15. Ford and Quam, *AIDS Quarantine: The Legal and Practical Implications*, 8 J. Legal Medicine 353, 370 (1987).

16. Gostin, *supra* note 3, at 1033; Parmet, *supra* note 1, at 82; Note: *The Constitutional Rights of AIDS Carriers*, 99 Harv. L. Rev. 1274 (1986).

17. *Id.*

18. Gostin, *supra* note 3, at 1028; American Bar Association, *supra* note 1, at 57.

19. Gostin, *supra* note 3, at 1033.

20. Gostin, *supra* note 3, at 1028-29, 1034; Gostin, *supra* note 5, at 1627; Parmet, *supra* note 1, at 85.

21. American Bar Association, *supra* note 1, at 57 n.85; Gostin, *supra* note 3, at 1037; Ford and Quam, *supra* note 15, at 396.

22. Gostin and Ziegler, *A Review of AIDS-Related Legislative and Regulatory Policy in the United States*, 15 Law, Medicine, and Health Care 5 (1987).

23. Gostin, *supra* note 3, at 1037.

24. American Bar Association, *supra* note 1, at 59 n.99; Or. Rev. Stat. sec. 433.001(6) (1987).

25. Gostin, *supra* note 3, at 1037; Parmet, *supra* note 1, at 85-87.

26. Gostin, *supra* note 3, at 1036; Gostin, *supra* note 5, at 1626-27.

27. Gostin, *supra* note 5, at 1626-27; Colo. Rev. Stat. 25-4-1406 (1988); American Bar Association, *Comprehensive Policy on AIDS*, Policy C5, promulgated by the AIDS Coordinating Committee, adopted by the House of Delegates on August 9, 1989.

28. Gostin, *supra* note 3, at 1037; Parmet, *supra* note 1, at 85-86.

29. Gostin, *supra* note 5, at 1630 n.108.

30. Conn. Gen. Stat. sec. 19a-221 (1987).

31. Gostin, *supra* note 5, at 1626.

32. American Bar Association, *supra* note 1, at 55 n.74.

33. *City of Cleburne v. Cleburne Living Center*, 735 F.2d 832 (5th Cir. 1984).

34. Gostin, *supra* note 3, at 34-35; Parmet, *supra* note 1, at 69-71; Merritt, *supra* note 14, at 9; *see New York Ass'n for Retarded Children v. Carey*, 612 F.2d 644 (2d Cir. 1979); *Cleburne*, 735 F.2d 832 (5th Cir. 1984).

35. American Bar Association, *supra* note 1, at 56; *Greene v. Edwards*, 263 S.E.2d 661 (W. Va. 1980).

36. American Bar Association, *supra* note 1, at 56; American Bar Association, *supra* note 27.

37. F. Grad, *supra* note 2, at 47-48.

38. Gostin, *supra* note 5, at 1626; Conn. Gen. Stat. sec. 19a-221 (1987); Or. Rev. Stat. sec. 433.019 - .025, .106 - .220 (1987); Ala. Code sec. 87-574 (1987).

39. Gostin, *supra* note 3, at 1032; *Youngberg v. Romeo*, 457 U.S. 307 (1982); *DeShaney v. Winnebago Co. Dept. of Social Services*, 109 S. Ct. 998 (1989); *Kirk v. Board of Health*, 83 S.C. 372, 378, 65 S.E.2d 387, 389 (1909).

40. S. Brakel, J. Parry, and B. Wiener, *The Mentally Disabled and the Law* 22 (1985).

41. Grad, *Communicable Disease and Mental Health: Restrictions of the Person*, 12 Am. J. Law and Medicine 381, 382 (1986).

42. S. Brakel, J. Parry, and B. Wiener, *supra* note 40, at 38-39, 129-36; F. Rovosky, *Consent to Treatment: A Practical Guide* 343 (1984).

43. S. Brakel, J. Parry, and B. Wiener, *supra* note 40, at 37-39; Ill. Ann. Stat. ch. 91 1/2 sec. 4-100-709 (Smith-Hurd 1981).

44. S. Brakel, J. Parry, and B. Wiener, *supra* note 40, at 56, 129-36.

45. *Parham v. J. R.*, 442 U.S. 584 (1979).

46. S. Brakel, J. Parry, and B. Wiener, *supra* note 40, at 26; Grad, *supra* note 41, at 395; K. Wing, *Public Health and the Law* 43 (1985).

47. American Bar Association, *supra* note 1, at 61.

48. Grad, *supra* note 41, at 396; S. Brakel, J. Parry, and B. Wiener, *supra* note 40, at 34-35, 72; *McClure v. State*, 737 P.2d 1001 (Utah 1987); *In the Matter of Commitment of B.S.*, 213 N.J. Super. 243, 577 A.2d 146 (1986).

49. Grad, *supra* note 41, at 396.

50. S. Brakel, J. Parry, and B. Wiener, *supra* note 40, at 72.

51. *Id.* at 55-74; American Bar Association, *supra* note 1, at 56.

52. *Donaldson v. O'Conner*, 422 U.S. 563 (1975).

53. *Youngberg v. Romeo*, 457 U.S. 307 (1982); *see* Wiedert, *Constitutional Rights of the Involuntarily Committed Mentally Retarded After Youngberg v. Romeo*, 14 St. Mary's L. J. 1113 (1983).

54. *Compare Clark v. Cohen*, 613 F. Supp. 684 (E.D. Pa. 1985); *Society for Goodwill to Retarded Children v. Cuomo*, 737 F.2d 1239 (2d Cir. 1984); *Thomas S. v. Morrow*, 601 F. Supp. 1055 (W.D. N.C. 1984).

55. Grad, *supra* note 41, at 399-400.

56. Parry, *Youngberg and Pennhurst II Revisited — Part I*, 10 MPDLR 154 (1986).

57. American Bar Association, *supra* note 27.

58. *Greene v. Edwards*, 263 S.E.2d 661 (W.Va. 1980).

59. American Bar Association, *supra* note 27, Policies C5, C6.

60. Intergovernmental Health Policy Project, *supra* note 10.

61. *Youngberg v. Romeo*, 457 U.S. 307 (1982).

62. *Id.*

63. American Bar Association, *supra* note 27.

VII. FEDERAL BENEFIT AND ENTITLEMENT PROGRAMS

This chapter reviews the major federal programs serving persons with disabilities with respect to how HIV infection affects eligibility determinations. Since these determinations are generally straightforward, at least as far as HIV is concerned, this chapter does not have general legal findings or a question and answer section.

The federal government has developed an elaborate network of programs and entitlements to help meet the diverse needs of persons with developmental disabilities. From health care to education, to vocational training and legal advocacy, these programs are intended to help persons with developmental impairments lead productive, independent lives in their communities.

By itself, HIV infection does not guarantee eligibility for most of these programs. Developmental impairments, either as a consequence of or unrelated to HIV infection, often will be a more important factor in determining eligibility. Thus, while children with asymptomatic HIV infection may qualify for services under the Early Childhood Education Act, they may be ineligible for special education services under the Education for All Handicapped Children Act if their symptoms do not require special education services. And regardless of the extent of impairment, financial means may be the key factor in determining eligibility for many programs.

1. Developmental Disabilities Programs

The Developmental Disabilities Assistance and Bill of Rights Act focuses on the needs of persons with severe, life-long disabilities that occur before adulthood. To qualify for funds under the Act states must meet certain requirements.[1] First, the Act requires each state to establish a developmental disabilities council to assist state agencies in planning and providing services to this population. Second, the statute provides grants to University Affiliated Programs (UAP's) to operate demonstration facilities and provide technical assistance and exemplary services, and to provide interdisciplinary training programs for personnel to work with persons with developmental impairments. Third, the Act authorizes each state to create a Protection and Advocacy System (P&A) to protect the legal rights of this population through a variety of means. The statute employs a functional definition of developmental disability: a "severe, chronic disability" that is manifest before age 22 and is likely to continue indefinitely. Additionally, the disability must cause "substantial functional limitations" in three or more areas of major life activity, which reflect the person's need for lifelong "individually planned and coordinated" services.[2]

Most infants and children with HIV infection will meet this definition because neurologic dysfunction is one of the common symptoms. The incidence of central nervous system dysfunction in infants and children with symptomatic HIV infection ranges from 78 to 90 percent.[3] Symptoms of the infection, and resulting developmental disabilities, usually appear by the time the child reaches the age of three. Persons with other pre-existing developmental impairments who contract the virus continue to qualify under this definition regardless of their age when they became infected. At this time, it is unclear whether non-disabled children and adolescents who contract the infection will meet the federal definition if they do not manifest significant symptoms before age 22.

Each client who is served under the Act must have a written individualized habilitation plan, stating long-term goals and intermediate objectives.[4] For persons with developmental disabilities who contract HIV, their habilitation plans may need to be amended to reflect their condition, and any resultant changes in habilitation, residential placement, or other services.

The actual services available through the federal Developmental Disabilities (DD) program are limited. The primary purpose of the UAP's is to train professionals; provision of exemplary services, which is primarily geared to young children, is a by-product of this purpose. However, several UAP's have seen significant numbers of children with AIDS, and provide diagnostic, therapeutic, and educational services. The P&A's provide a variety of legal and advocacy services, but with limited resources they must restrict the number of clients they choose to assist. Like the UAP's, many of the P&A's have intervened on behalf of persons with HIV infection and developmental disabilities, including cases involving discharge from institutions and appropriate community care, and denial of access to schools, developmental centers and group homes. They also have helped developmental facilities devise confidentiality procedures.

The DD councils provide no direct services, although they may contract with direct service agencies. Given the functional focus of the federal definition, the councils could play a critical role in alerting state agencies, such as child welfare, social services, and education departments, to the expected increase in children with AIDS requiring specialized services. Many agencies may not consider AIDS to be a developmental disability, or may need assistance to meet the specialized needs of children with HIV infection. Given the fear surrounding AIDS, some states may consider providing a separate system of care. Yet, children with HIV infection share many of the same developmental characteristics as children with other disabilities. Moreover, separate systems of care may violate section 504 of the Rehabilitation Act, state antidiscrimination statutes, and even the U.S. Constitution.

2. Education Programs

a. The Education for All Handicapped Children Act

As students who are "handicapped" under the Education for All Handicapped Children Act (P.L. 94-142), children with developmental impairments are guaranteed free, appropriate educational services.[5] Any state accepting funding under the Act must provide a "free, appropriate public education" to all disabled children. The Act spells out numerous procedural and programmatic requirements, including that children be educated in the "least restrictive environment."

The statute's definition of "handicap" and its effect on the right to educational services was examined in Chapter III. P.L. 94-142 requires schools to provide "special education and related services" to qualified handicapped children. Related services are defined as "support services that may be required to assist a handicapped child to benefit from special education."[6] Such services include counseling, special transportation, and physical and occupational therapy. Related services may also include residential placements where such a placement is necessary to educate the child. Certain medical services also may qualify under this definition, which could be especially important for children with HIV infection.[7] However, courts have held that P.L.

94-142 does not require school districts to provide constant in-school nursing care to severely disabled children.[8]

Before filing a lawsuit in federal court for violation of rights under P.L. 94-142, a child must exhaust all administrative remedies available under the statute unless to do so would be futile.[9] Pursuing administrative remedies can be a lengthy process, and thus particularly detrimental to children with AIDS who may die or lose precious time before receiving the appropriate educational services to which they are entitled.

b. Early Childhood Education Programs

The primary focus of P.L. 94-142 is on children between the ages of 3 and 21. Yet, infants with symptomatic HIV infection can present a range of developmental impairments requiring early intervention. The Education of the Handicapped Act Amendments of 1986 (P.L. 99-457) require states receiving federal funds under the infant, toddler, and preschool programs to provide: 1) early intervention services to infants and toddlers, ages 0-2, and 2) special education programs and related services to children ages 3 to 5.[10] Many infants and toddlers with symptomatic HIV infection experience developmental delays, loss of developmental milestones, or intellectual deficits requiring early intervention in order to assist future learning capabilities.[11]

Early intervention services are designed to identify and treat an educational problem or deficit as early as possible. These developmental services, which can be provided in the child's home, a clinic, or the local health department, include services addressing physical development, cognitive development, language and speech development, psycho-social development, and self-help skills. P.L. 99-457 requires that these services be implemented by school year 1991-92.

P.L. 99-457 defines "handicapped infants and toddlers" as children between the ages of 0 and 2 who require early intervention services either because: 1) they are experiencing developmental delays, or 2) they have a diagnosed physical or mental condition which has a "high probability of resulting in developmental delay."[12] Additionally, the statute allows states, but does not compel them, to include children who are "at risk of having substantial developmental delays if early intervention services are not provided." P.L. 99-457 does not define "developmental delay," leaving the states free to define the term.[13]

How states define "developmental delay" could prove critical in helping children with HIV infection gain access to services and programs. First, infants who are known to be infected with HIV could qualify under the federal definition since research shows that such children have a "high probability" of presenting developmental impairments.[14] Secondly, if a state adopts the broader definition, infants determined to be "at risk" of having HIV could qualify for services. The "at risk" qualification will be important for babies who test positive in their first 15 months, yet show few other symptoms of infection, since the possibility exists that the baby has merely acquired her mother's HIV antibodies but not the virus itself. Such an infant would not have a diagnosed condition at this point, thus failing to meet the first or second parts of the federal definition. Under the optional "at risk" definition, however, a child would not be denied services while awaiting a definitive test result or presentation of certain symptoms to confirm a diagnosis of HIV infection. Fourteen states have included children "at risk" within their definition of disabled infants and toddlers; several other states are providing services to "at risk" infants on a pilot basis.[15]

Similar to P.L. 94-142's provision of "related services," P.L. 99-457 authorizes states to provide "health services necessary to enable the infant or toddler to benefit from the other early intervention services."[16]

3. Vocational Rehabilitation Programs

a. Vocational Rehabilitation Services

Title I of the Rehabilitation Act of 1973 authorizes a federal-state program to provide comprehensive vocational rehabilitation services to individuals with disabilities. The Act defines such services as "any goods or services necessary to render an individual with handicaps employable;" this may include evaluation and diagnostic services, medical services, counseling, referral and placement, training, and prosthetic devices or other technological aids.[17] The statute requires rehabilitation counselors and their clients to develop annual individualized rehabilitation plans specifying short and long term goals, as well as which services and aids will be provided.

For purposes of determining eligibility for rehabilitation services, the Act uses a functional definition. An "individual with handicaps" is anyone who "(i) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (ii) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services."[18] Significantly for persons with developmental disabilities, the Act requires states to focus efforts on persons with "severe handicaps." This refers to persons who have severe physical or mental disabilities which seriously limit one or more functional capacities (such as mobility, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills) in terms of employability. The Act provides a list of disabilities potentially covered by this definition, including several which are or may be developmental impairments, such as cerebral palsy, mental retardation, and neurological disorders.[19]

In 1986, the Rehabilitation Services Administration (RSA) issued a policy memorandum that permitted state vocational rehabilitation agencies to deny services to persons with AIDS because they were likely to die before they could benefit from the services. This policy is being re-examined, and RSA is expected to publish a new policy in 1990.

The fact that an individual has both a developmental impairment and HIV infection does not alter her eligibility for services, as long as she meets the statute's definition of "handicaps." Vocational rehabilitation programs must not deny an eligible individual services on the basis of her HIV infection; otherwise the program is in violation of section 504.

b. Client Assistance Program

The Rehabilitation Act requires each state to establish a Client Assistance Program (CAP), to help ensure that persons with disabilities receive assistance in obtaining information and access to rehabilitation services.[20] The purpose of CAP is to advise vocational rehabilitation applicants and clients about all available services under the Rehabilitation Act, to assist them in their relationships with programs and facilities providing rehabilitation services, and, if necessary, provide assistance in obtaining legal, administrative and other appropriate remedies. In many states, CAP's are designated as part of the P&A system, but in other states they are independent

agencies or part of departments of vocational rehabilitation. Anyone eligible for rehabilitation services is eligible to receive assistance from a CAP.

4. Social Security Programs

a. Social Security Disability Income (SSDI)

This program provides basic income support to disabled persons unable to work as a result of their impairment. SSDI benefits are only available to a worker who has paid into the Social Security system, or to the spouse or children of the worker upon her retirement, disability, or death. Usually, benefits to children cease when the child is 18 or 19. However, if the child is disabled before the age of 22, eligibility continues without regard to age.[21]

Generally, persons are eligible for SSDI benefits if they can prove an inability to engage in "substantial gainful activity" (employment) because of a medically certified physical or mental condition which is expected to last for at least 12 months, or result in death.[22] In addition, the Social Security Administration (SSA) rules provide coverage for anyone meeting the Centers for Disease Control (CDC) surveillance definition of AIDS; they are presumed to be disabled.[23] Thus, individuals diagnosed with one of the opportunistic infections included on the CDC list of conditions indicating AIDS would be immediately eligible for benefits, provided they meet the income qualifications. Persons who are HIV-positive, but do not have AIDS, must prove that they have a disabling condition that prevents them from working.

b. Supplemental Security Income (SSI)

This program provides monthly financial support to aged, blind, and disabled persons who have limited income and resources.[24] SSI uses the same standard of disability as SSDI -- inability to work due to a physical or mental impairment that is expected to last 12 months or result in death. Children under 18 may qualify for SSI benefits if an adult with their disability would be unable to work. This means that a child must have a severe, medically determinable physical or mental impairment that can be expected to result in death, last for at least 12 months, or is of comparable severity.[25] The SSI program, like SSDI, treats persons diagnosed with AIDS as presumptively eligibile for benefits.[26]

5. Health Care Financing

a. Medicare

Medicare is a federal medical insurance program, primarily serving people aged 65 and older.[27] However, Medicare is available to persons with developmental disabilities who receive SSDI benefits under the Adult Disabled Child Program. Therefore, Medicare could be a source of financing for those individuals with developmental disabilities who contract HIV and do not qualify for Medicaid benefits. For persons under age 65, Medicare imposes a two-year waiting period; an individual must have a disability for two years before they are eligible to receive benefits. If a person with a developmental impairment is already receiving Medicare benefits when they are diagnosed with HIV, there is no problem because the 24-month waiting period applies only to the initial application to the program.

The two-year waiting period can effectively deny Medicare benefits to persons who would otherwise be eligible, since currently people with AIDS often die within two years of diagnosis. Legislation has been introduced in Congress to eliminate the two year waiting period for persons with AIDS. Proposed legislation would also authorize payment for experimental treatments, which are usually not covered under the program.

b. Medicaid

Medicaid is a joint federal-state endeavor, reimbursing health care providers for services provided to financially, and in some cases, medically needy qualified recipients.[28] However, financial need, not medical diagnosis, is the primary eligibility requirement. A person receiving SSI benefits is automatically eligible for Medicaid.[29] Similarly, many children placed in foster care are eligible for Medicaid benefits.[30] Persons with AIDS are presumed to be disabled for purposes of Medicaid eligibility. States are given discretion to determine precise eligibility requirements, as well as exactly what medical costs may be reimbursed by Medicaid funds. Thus, while some states have decided to pay for the anti-AIDS drug zidovudine (AZT), other states have refused, or limited the extent to which they will reimburse such costs.[31]

Two programs within Medicaid are of special importance to persons with developmental disabilities and HIV infection. The Intermediate Care Facility/Mental Retardation (ICF/MR) Program authorizes reimbursement to these facilities for care and treatment of Medicaid-eligible persons with developmental disabilities.[32] The U.S. Health Care Financing Administration (HCFA) has responsibility for overseeing and regulating these residential programs. The regulations governing these facilities prohibit segregation of clients on the basis of their physical disability, instead requiring that individuals be integrated with others of comparable social and intellectual development.[33] Facilities receiving Medicaid funds may not segregate a client with a developmental disability solely because of her HIV status.

The Medicaid ICF/MR program historically was geared to supporting long-term institutional care and treatment of persons with developmental disabilities. However, a 1981 amendment authorized HCFA to grant states waivers to fund alternative, community-based or home care and related services.[34] In order to obtain a waiver a state must first prove that its proposed alternative services would be less expensive than institutional care. States have discretion about the types of services to fund under the waiver; these can include residential services, respite and home health aide programs, adult day care, homemaker services, occupational and physical therapy, nursing care, transportation services, and case management. Many of these services will help persons with HIV infection remain in community facilities.

HCFA has granted waivers to New Jersey, California, Ohio, New Mexico and Hawaii to provide targeted health care and related services to persons with HIV infection.[35] Texas, initially denied a waiver, planned to resubmit its application in June 1989.[36] Under New Jersey's waiver, Newark is providing services to children with HIV infection under five years old, and to children with AIDS or ARC of any age.[37]

6. Child Welfare Programs

The most significant piece of federal child welfare legislation is the 1980 Adoption Assistance and Child Welfare Act, P.L. 96-272 (AACWA).[38] This is a funding statute which

helps support the state child welfare and foster care system. However, to be eligible for federal funds, a state must comply with certain requirements, many of which address individual case handling. For example, before a child is removed from his or her home by forceful state intervention, "reasonable efforts" (as found by a court of law) must have been made to avoid removal. This would include the provision of services to the family which would remedy the problems, if possible. Thus for example, if the child has a mother who is HIV-positive, the state may need to provide homemaker or temporary respite services to assist the mother if she experiences periodic episodes of sickness but is generally capable of functioning as a parent.

For every child removed from home, a written case plan must be developed. This plan must address the services to be provided the child and family by the state, and the responsibilities of the parents. Every child in state care will have his status reviewed by a court or administratve body after six months, and by a court after 18 months. In addition to these planning activities, every child in foster care is entitled to services necessary for proper maintenance of health and well-being. Many children are eligible for Medicaid payments.[39] This may include access to specialized foster care services in which foster parents are specially trained to deal with a child's medical condition or disability. Many states, recognizing the increased costs and responsibilities of caring for a child with a disability, use their federal dollars to pay a higher reimbursement rate for foster children with disabilities, including HIV infection.[40]

The provisions of the AACWA apply equally to all children, regardless of whether they have a disability such as HIV infection. Thus, child welfare agencies must develop individualized case plans for every HIV-positive child in its care, even if the likelihood of death appears to be extremely high. The presence of HIV, of course, may affect the details of the plan. However, it would be illegal to develop plans which routinely isolate or treat HIV-positive children as "special" cases. The AACWA requires that children removed from their home be placed in the least restrictive setting.

FOOTNOTES - FEDERAL BENEFIT AND ENTITLEMENT PROGRAMS

1. 42 U.S.C. secs. 6000-6083.
2. 42 U.S.C. sec. 6001(7).
3. Diamond and Cohen, *HIV Infection in Children: Medical and Neurological Aspects*, Technical Report of the American Association of University Affiliated Programs 2 (May 1989).
4. 42 U.S.C. sec. 6011(b).
5. 20 U.S.C. secs. 1232, 1400, 1401, 1405-20, 1453.
6. 20 U.S.C. sec. 1401(17).
7. *Irving Independent School District v. Tatro*, 468 U.S. 883 (1984).
8. *Detsel ex rel. Detsel v. Board of Education of the Auburn Enlarged City School District*, 637 F. Supp. 1022 (N.D.N.Y. 1986).
9. 20 U.S.C. sec. 1415(e); *see, e.g., White v. Western School Corp.*, No. IP85-1192-C, slip op. at 4 (S.D. Ind. Aug. 23, 1985).
10. 20 U.S.C. secs. 1401, 1408, 1411-13, 1418-19, 1421-25, 1431-33, 1441, 1461-62, 1471-85.
11. *See* Diamond and Cohen, *supra* note 3, at 2-3.
12. 20 U.S.C. sec. 1472(b)(1).
13. 20 U.S.C. secs. 1472(b)(1), 1476(a).
14. *See* Diamond and Cohen, *supra* note 3, at 2-3.
15. United Cerebral Palsy Associations, Word from Washington, April-May 1988 at 15.
16. 20 U.S.C. sec. 1472(b)(2)(E).
17. 29 U.S.C. sec. 723(a).
18. 29 U.S.C. sec. 706(8)(A).
19. 29 U.S.C. sec. 706(15)(A).
20. 29 U.S.C. sec. 732.
21. 42 U.S.C. sec. 402(d)(1).
22. 42 U.S.C. sec. 416(i).
23. 20 C.F.R. sec. 416.934(k).
24. 42 U.S.C. sec. 1381 *et seq.*
25. 42 U.S.C. sec. 1382c(a)(3)(A).
26. 42 U.S.C. sec. 1383(a)(4)(B).
27. 42 U.S.C. sec. 1395 *et seq.*
28. 42 U.S.C. sec. 1396 *et seq.*
29. 42 U.S.C. sec. 1396a(10)(A).
30. 42 U.S.C. sec. 673(b).
31. *See Weaver v. Reagen*, 701 F. Supp. 717 (W.D. Mo. 1988).
32. 42 U.S.C. secs. 1396d(c), (d). Medicaid eligibility extends to those children for whom either foster care maintenance or adoption assistance payments are made.
33. 42 C.F.R. sec. 483.470.
34. 42 U.S.C. sec. 1396n(c)(4)(B).
35. U.S. General Accounting Office, *Pediatric AIDS: Health and Social Service Needs of Infants and Children*, 8-9 (1989); Intergovernmental Health Policy Project, The AIDS Policy Center, Intergovernmental AIDS Reports, Oct.-Nov. 1989 at 2.
36. U.S. General Accounting Office, *supra* note 35, at 9.
37. *Id.*
38. Pub. L. No. 96-272, 94 Stat. 500 (1980) (codified in scattered sections of 42 U.S.C.).
39. See n.32, *supra*.
40. U.S. General Accounting Office, *supra* note 35, at 9.

GLOSSARY

Acquired Immune Deficiency Syndrome (AIDS): An acquired illness of the immune system which reduces the body's ability to fight special types of infection and cancers. The Human Immunodeficiency Virus (HIV) is the cause of this illness which is transmitted through intimate sexual contact, in particular, anal and vaginal intercourse; direct exposure to or infection with infected blood or blood products; and from an infected woman to her fetus or infant. The data on oral sexual transmission are unclear. Once the immune system is impaired, persons who are diagnosed as having AIDS may easily develop one or more specific opportunistic infections or rare cancers which become life-threatening. Of persons officially diagnosed as having AIDS for three or more years, over 80 percent have died.

Specific diseases must be present to be diagnosed officially as AIDS and to be reported to the Centers for Disease Control. In general, the diseases include unusual forms of bacterial, fungal and viral infections as well as rare cancers.

AIDS Dementia Complex: A degenerative disorder of the brain and central nervous system caused by infection with HIV that leads to progressive deterioration of mental and neurological functions. AIDS dementia is reported to occur in approximately 70 percent of AIDS patients. It can also affect patients with AIDS-Related Complex, and some individuals who are infected with the HIV. Symptoms include: memory loss, mood shifts, depression, difficulty in concentrating, and motor impairment, including difficulty walking and weakness in arms and legs.

AIDS-Related Complex (ARC): After being infected with the virus, some people may not develop the specific, life-threatening conditions used to identify AIDS. They may, however, develop other illnesses and symptoms which indicate that their immune responses are impaired. Symptoms may include weight loss, chronic fatigue, lethargy, swollen glands, persistent diarrhea, low-grade fevers and oral thrush.

Antibody: Special protein developed by the body's immune system in response to exposure to specific foreign agents. A given antibody exactly matches a specific agent that causes an infection, much like a key matches a lock; the antibody then helps to destroy the infectious agent.

Asymptomatic HIV Infection: Without subjective or objective signs of illness. People who are infected with HIV, as evidenced by the presence of HIV antibodies, may show no symptoms of disease.

Body Fluids: Any fluid of the human body, including blood and blood products, semen, vaginal secretions, breast milk, tears, sweat, saliva, urine, etc. Only blood and blood products, semen, vaginal secretions and, rarely, breast milk have been associated with transmission of HIV.

Blood Products: Components of blood, such as plasma, white blood cells, and red blood cells. Blood may be segregated into its components for use in health treatments.

Casual Contact: Refers to day-to-day interactions between HIV-infected individuals and others in the home, at school, or in the workplace. It does not include intimate contact, such as sexual or drug use interactions, and it implies closer contact than chance passing on a street or sharing a subway car.

Communicable or Contagious Disease: An illness caused by a specific infectious agent (i.e., a virus, bacteria, fungus) that is transmitted, directly or indirectly, from an infected person to another person.

Congenital or Prenatal Transmission: Transmission of infection occurring prior to birth, causing an infant to be born with the infection.

Developmental Disability: As defined by the federal Developmental Disabilities Assistance and Bill of Rights Act, a developmental disability is a severe, chronic disability which:

a) is attributable to a mental or physical impairment or combination of mental and physical impairments;

b) is manifested before age 22;

c) is likely to continue indefinitely;

d) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated; and

e) results in substantial functional limitations in three or more of the following major life activities:

1. self-care
2. receptive and expressive language
3. learning
4. mobility
5. self-direction
6. capacity for independent living
7. economic sufficiency.

Dideoxyinosine (ddI): A drug recently identified by the Food and Drug Administration as showing promise in treatment of persons with HIV infection. DdI may be available for use as an alternative to zidovudine (AZT) when AZT has proven toxic or ineffective.

Enzyme Linked Immunoabsorbent Assay (ELISA) Test: A simple, rapid, sensitive blood test that measures antibodies to HIV proteins. The ELISA test was licensed by the Food and Drug Administration in 1985 to screen blood supplies only. As a blood screening test, the ELISA is highly sensitive to detecting HIV antibodies. ELISA's are usually repeated if the first test is positive. If the patient tests positive a second time, then a more specific test, the Western Blot, is performed to confirm the results.

Encephalitis: Inflammation of the brain.

Encephalopathy: Any degenerative disease of the brain.

Failure to Thrive: A condition in which an infant exhibits general chronic poor health and an inability to achieve usual developmental progress.

Habilitation: Process by which various professional services are utilized to help an individual with a developmental disability make maximal use of his capacities in order that he might learn

to function more effectively and independently. This process seeks the remediation of the delayed learning process of a developmentally disabled person. Habilitation encompasses the acquisition of self-help, language, personal, social, educational, vocational, and recreational skills.

HIV Positive: When test results from an individual indicate presence of HIV infection. Commonly, to be considered positive for HIV infection, a person with HIV antibodies must have two positive ELISA tests confirmed by a positive Western Blot test.

Human Immunodeficiency Virus (HIV): The specific AIDS virus which has been identified as destroying the body's immune system, making a person susceptible to life-threatening, opportunistic infections or rare cancers. The HIV is believed to be a relatively new virus. It is particularly resistant to treatment, as the HIV genetic material is incorporated into the healthy genetic material of the blood cells and is reproduced. Because the HIV genetic material is reproduced, individuals who are infected with the virus remain carriers for the rest of their lives. The virus also has a long incubation period. Thus, it may be a long time between the point when a person is infected and when the antibodies can be detected (anywhere from three weeks to six months). It may also take up to five years or more before HIV-related symptoms become apparent and are diagnosed.

Immune System: The natural system of defense mechanisms, in which specialized cells and proteins in the blood and other body fluids work together to eliminate disease-producing micro-organisms and other foreign substances.

Incubation Period or Latency Period: The time period over which a disease exists without any symptoms appearing or the time period from the point of infection to showing clinical signs of the disease. Based on current data, the latency period for the AIDS virus is estimated to range up to ten years.

Infection Control Procedures: Procedures recommended by the federal Centers for Disease Control for use in preventing HIV transmission, as well as other infectious diseases, such as hepatitis B. These procedures should be applied to all individuals in a facility regardless of HIV status. Procedures include, but are not limited to: wearing gloves when working with blood, semen, or vaginal secretions and cleaning up blood spills with disinfectants. **Universal precautions** are a specific set of infection control procedures recommended for use in health care settings.

Infectious Disease: An illness that results from the entry, development or multiplication of a disease-causing organism. Not all infectious dieases are highly contagious or easily communicable to other people. Although HIV is caused by infection with a virus, the virus is not easily or casually transmitted.

Interstitial Pneumonitis: Localized acute inflammation of the lung. Interstitial pneumonitis persisting for more than two months in a child (under 13 years of age) is indicative of AIDS unless another cause is identified or tests for HIV are negative.

Intravenous Gamma Globulin: Treatment in which gamma globulin, the protein portion of blood plasma which contains most of the blood's antibodies, is fed directly into the bloodstream of a patient. Intravenous delivery of gamma globulin has shown promise as a treatment for infants with HIV infection.

Kaposi's Sarcoma: A cancer or tumor of the blood and/or lymphatic vessel walls. Before the appearance of AIDS, Kaposi's sarcoma was rare in the United States and Europe, where it occurred primarily in men over age 50 or 60, usually of Mediterranean origin. AIDS-associated Kaposi's sarcoma is much more aggressive than the earlier form of the disease.

Lymphadenopathy: A condition characterized by persistent, generalized swollen glands in the absence of any current illness or drug use known to cause such symptoms.

Needlestick Injury: Accidental puncturing of the skin with a hypodermic needle after the needle has been used in treatment.

Opportunistic Infection: An infection caused by an organism that rarely causes disease in persons with normal immune systems but attacks immunosuppressed patients. Infections common in persons with AIDS include toxoplasmosis, pneumocystis carinii pneumonia, cytomegalovirus, and tuberculosis.

Pediatric AIDS: Clinical AIDS in children under 13.

Perinatal Transmission: Transmission of an infection occurring during pregnancy, or during the first 28 days of life.

Pneumocystis Carinii Pneumonia: The most common life-threatening opportunistic infection diagnosed in persons with AIDS. It is caused by the parasite Pneumocystis carinii.

Risk Factors or Risk Taking Behavior: Any personal characteristic or behavior that increases the likelihood that a person will be affected by a given condition. The risk factors that are known to increase the chances of transmitting HIV infection include engaging in intimate sexual contact (in particular, vaginal or anal intercourse) without a condom, sharing intravenous needles, and other activities which involve the exchange of infected body fluids. Co-factors are additional characteristics or other conditions that work with other risk factors to increase the chances of getting a disease. For instance, having a diagnosed sexually transmissible disease or already weakened immune system are believed to be co-factors which increase the chances of being infected with HIV.

Sexually-Transmitted Disease: Infection which may be transmitted from one partner to another via sexual contact.

Symptomatic HIV: HIV infection accompanied by symptoms and conditions related to AIDS.

T-Helper Lymphocyte (T-Cell): A type of white blood cell that is essential to the body's immune system in its fight against infection. T-cells help regulate the production of substances called antibodies. T4 lymphocytes are a special subset of T-cells. T4 cells start the body's immune response and help the body protect itself against viruses, parasites, tumors and fungi. The HIV interferes with the function of the T4 cells.

Transmission: The way in which a disease can be transferred from one person to another or the way in which a person is exposed to the disease. The HIV may be transmitted in three main ways:

* through intimate, unprotected sexual contact.
* through parenteral exposure (through injections with contaminated or unsterilized needles). This primarily occurs with drug users who share needles when injecting

drugs. Injection with contaminated blood products, through blood transfusions received before 1985, was also a route of transmission. Today, due to available blood testing techniques, the risk of transmitting HIV through infected blood or blood products is extremely miniscule.

* through perinatal transmission (transfer of HIV from the mother to the infant) either (a) through the placenta before the infant is born; (b) during the birth process itself; or (c) soon after birth through breast milk. Studies are still being conducted to see which mode of transmission occurs most frequently. It is currently estimated that there is up to a 50 percent chance that an infected mother will pass the virus to her child. The risk of perinatal transmission is believed to be higher if the mother is, or becomes, seriously ill during her pregnancy.

Unprotected Sexual Contact: Engaging in sexual relations without taking precautions against transmission of sexually-transmitted diseases.

Western Blot Technique: A test that involves the identification of antibodies against specific protein molecules. This test is believed to be more specific than the ELISA test in detecting antibodies to HIV in blood samples; it is also more difficult to perform and considerably more expensive. Western blot analysis is used as a confirmatory test after two positive ELISA tests.

Zidovudine (AZT): A drug used to enhance the body's immunologic response. The Food and Drug Administration has approved AZT for prescription to persons with T4 cell levels of 200 or less who have experienced one or more episodes of pneumocystis carinii pneumonia. In August, 1989 the National Institute of Allergy and Infectious Diseases recommended prescribing AZT to all persons infected with HIV who have T4 cell levels of 500 or less. AZT has shown promise in prolonging the asymptomatic period for HIV infected persons.

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